THE EXPERIENCES OF PARENTS WHO HAVE AN ADOLESCENT WITH INTELLECTUAL DISABILITY IN GIYANI

by

TSAKANI CHAUKE

Minor Dissertation submitted as partial fulfilment for the degree

MASTERS IN NURSING SCIENCE

In

PSYCHIATRIC MENTAL HEALTH NURSING

In the

DEPARTMENT OF NURSING

FACULTY OF HEALTH SCIENCES

At the

UNIVERSITY OF JOHANNESBURG

Supervisor: Prof M Poggenpoel
Co-Supervisor: Prof CPH Myburgh
Co-Supervisor: Dr N Ntshingila

September 2019

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DEDICATION

I dedicate this Minor Dissertation to my family and colleagues. Thank you for your support and encouragement throughout my studies. Your love, patience and belief in me made me persevere, stay positive and complete my studies

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To God for giving me the opportunity to do this minor dissertation and for giving me the strength and ability to finish my studies.

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ABSTRACT

Parents who have an adolescent with intellectual disability experienced stress caused by challenges that came with having such adolescents. Those challenges affected the parents physically and emotionally, depending on the severity of the adolescent's disability. To have an adolescent with intellectual disability become a burden if the challenges are not resolved.

The purpose of the study was to describe the experiences of parents who have an adolescent with intellectual disability in Giyani, and to develop recommendations to facilitate these parents' mental health. A qualitative, exploratory, descriptive, contextual design was utilised in this study. Data were collected through in-depth, phenomenological interviews with eight participants, observations and field notes. The main question asked of participants was "How is it to have an adolescent with intellectual disability?" Collected data were analysed through thematic coding and with the assistance of an external coder.

Parents who have an adolescent with intellectual disability experienced negative emotional responses. Most parents reported a lack of support from their family members and the community, while few parents reported an abundance of support from their family members and the community. They also reported caring challenges, and some showed positive coping mechanisms.

The researcher developed recommendations to facilitate parents' mental health. The recommendations were developed to enhance the parents' wholistic well-being. Recommendations include conducting psychotherapy with the parents and the community, and government and stakeholders providing resources, including the private sectors.

TABLE OF CONTENT

CHAPTER 2

RESEARCH DESIGN AND METHOD

CHAPTER 3

RESULTS: THE EXPERIENCES OF PARENTS WHO HAVE AN ADOLESCENT WITH INTELLECTUAL DISABILITY IN GIYANI

CHAPTER 4

LIMITATIONS, RECOMMENDATIONS AND CONCLUSIONS

TABLES

ANNEXURES

CHAPTER 1
INTRODUCTION, RATIONALE AND OVERVIEW

1.1 INTRODUCTION

Intellectual disability is a disorder with onset during a child's developmental period. It includes both intellectual and adaptive functioning deficits in conceptual, social, and practical domains (American Psychiatric Association, 2013:33). In 1986 the term 'mental retardation' was changed to 'mental handicap'. This was later changed to 'intellectual disability' in 2000, though some people continue saying 'mental retardation' (Foskett, 2014:7).

Children with intellectual disabilities are cared for by their parents who serve as their most constant and life-long caregivers (Families Special Interest Research Group (SIRG) Position Paper, 2012:2). They play a critical role in shaping the development and life experiences of their children with intellectual disabilities. In many contexts, parents' involvement extends over their lifespan (Families SIRG Position Paper, 2012:2).

Parents play a major role in helping children grow and develop to their full potential. As children grow and develop, they significantly depend on their parents for their basic needs. Intellectual disablement in children during adolescence can be very disturbing, requiring proper attention, help and support from parents. Thus, parents of adolescents with intellectual disabilities have additional responsibilities and roles in caring for them. These children could be dependent on their parents for the rest of their lives.

Caring for a person with intellectual disability can be a very enriching and positive experience, but it can also be challenging, demanding and filled with pressure (Lafferty, O'Sullivan, O'Mahoney, Taggart & van Bavel, 2016:29). Children with severe intellectual disabilities living in rural areas often have a low life expectancy due to a lack of care, support and access, even to the most basic services. These parents are seldom able to meet the additional financial burden of regular visits to hospitals,

additional expenses for equipment and assistive devices, and other necessaries (Foskett, 2014:9).

Parents' caregiving in the field of intellectual disability has received increased attention over the last few years, yet relatively little is still known about caregiving demands, family relationships, family supports, and compound caregiving prioritisation. If parents are to be supported in their caring role, it is important for health professionals to develop a better understanding both of the demands they face, and of the mechanisms that allow them to continue their role to care for their children with intellectual disabilities (Lafferty, et al. 2016:26). An adolescent with intellectual disability requires specialized attention as they remain dependent for the rest of their lives.

1.2 BACKGROUND AND RATIONALE

It has been estimated that 1-2% of the world's population have intellectual disabilities, with a higher prevalence reported among children and adolescents, and in lower-income countries (Maulik, Mascarenhas, Mathers, Dua & Saxena, 2011:32). Given the current global fertility rate of 2.5%, this suggests that globally, 1 in 50 parents have a child with intellectual disabilities (United Nation Children Fund (UNICEF), 2011:1). Ninety per cent of the world's children aged 0 – 14 live in low- or middle-income countries (World Bank, 2012:3). While intellectual disability has an estimated prevalence of between 2% and 3% in developed countries, a study in areas of South Africa found a prevalence rate of 3.6% (Foskett, 2014:4).

In the vast majority of instances, adolescents with intellectual disabilities are cared for by their parents who serve as their most constant and life-long caregivers. Parents play a critical role in shaping the development and life experiences of their adolescents with intellectual disabilities. In many contexts, parents' involvement extends over their life span, with siblings and extended family members taking on caring roles, especially when parents are no longer able to (United Nations, 2011:464; World Health Organization Regional Office for Europe, 2010:14).

The International human rights conventions require member states of the United Nations to make an effort in ensuring that when a parent cannot care for a child,

alternative arrangements are made either with the adolescent's extended family or in substitute family settings in the community (United Nations, 2011:465). The continuing reliance in some countries on institutional care for a majority of children with intellectual disabilities is a source of major concern (United Nations, 2011:465; World Health Organization Regional Office for Europe, 2010:14).

In some cultures, parents of a child with disabilities may differ from parents who do not have a child with disabilities, in various important ways (United Nations, 2011:465). These include an increased risk of exposure to socio-economic disadvantage; exposure to disability-related discrimination; coping with exceptional and prolonged caring tasks; complex interactions with disability services; and continuing to provide support into later childhood, adolescence and adulthood. Parents are likely to vary as a function of social and cultural context and the nature and severity of the child's impairment (United Nations, 2011:465). In addition, due to the lack of reliable statistics, there is a paucity of published literature on intellectual disability in South Africa. The lack of evidence-based publications precludes an accurate description of the prevailing epidemiology and burden of intellectual disablement in South Africa (Foskett, 2014:5).

1.3 PROBLEM STATEMENT

Holloway and Galvin (2017:3) describe a research problem as a statement about what researchers want to find out, and it stems directly from a problem experienced in the clinical area or in their personal and professional lives. Intellectual disability is a life-long condition, and the management thereof must constantly be adapted to satisfy the needs of the individuals affected. A knowledge gap on the experiences of parents who have an adolescent with intellectual disability has led the researcher to this study, where a qualitative design was used (Rebar & Gersch, 2015:48). Most of the adolescent with intellectual disability who are admitted in the psychiatric hospital were rarely taken for leave by their parents, that was the reason why the researcher wanted to understand the experiences of their parents. The researcher explored the experiences of the individual parents in order to gain an improved understanding of these experiences.

A child with an intellectual disability poses a challenge to their parents. Intellectual disability can be thought of as a disorder which affects not only the person with the disorder but also those around them, although friends and family members may not understand the special needs of the adolescent with intellectual disability. There is extensive literature that examines the stress on parents of patients with intellectual disability who care for them, but there is a gap in the description of the extent of the experiences that these parents endure in South Africa (Adams, 2010:436). It is imperative that the information gap on the burden of adolescents with intellectual disability on parents be recognised in order to plan for the needs of those with intellectual disability across their lifespan (Adams, 2010:436). The research questions that arose from this problem statement were:

- What are the experiences of parents who have an adolescent with intellectual disability?
- What are the recommendations to facilitate these parents' mental health?

1.4 RESEARCH PURPOSE

The purpose of this study was to describe the experiences of parents who have an adolescent with intellectual disability in Giyani, and to develop recommendations to facilitate these parents' mental health.

1.5 RESEARCH OBJECTIVES

The objectives of this study were:

- To explore and describe the experiences of parents who have an adolescent with intellectual disability in Giyani.
- To describe recommendations for the facilitation of the mental health of parents who have an adolescent with intellectual disability in Giyani.

1.6 PARADIGMATIC PERSPECTIVE

A paradigm is a set of basic beliefs that guide action (Creswell, 2014:6). Lincoln and Guba (1994:105) use the term 'paradigm' for essentially the same thing, defining a paradigm as a basic belief system or worldview that guides the researcher, not only in the choices of the method but in ontologically and epistemologically fundamental ways. Creswell (2014:6) defines a 'worldview' as a general philosophical orientation about the world and nature of research that the researcher brings to the study. Lincoln and Guba (1994:105) emphasise that the consideration of paradigms precedes the considerations of methods (Lor, 2011:1).

The paradigm is discussed under the following sub-headings: meta-theoretical assumptions, theoretical assumptions and methodological assumptions.

1.6.1 Meta-theoretical assumptions

Meta-theories are defined as theories about the description, investigation, analysis or criticism of the theories in a domain. They are mostly internal to a domain, and may also be termed 'paradigms', 'traditions' or 'schools' (Lor, 2011:1). Meta-theoretical assumptions are conscious assumptions behind theoretical, empirical, and practical work; they connect to philosophical views and are often parts of the interdisciplinary trends (Mattson & Haas, 2014:13). Intellectual disability is something that is framed in a number of different ways with very different implications for knowledge, policies and practices (Kamlager, 2013:28). The researcher used the assumptions embedded in the Theory for Health Promotion in Nursing (University of Johannesburg, 2017:4). These assumptions include the person, mental health, the environment and psychiatric nursing.

1.6.1.1 Person

The person is seen wholistically, embracing the body, mind and spirit, and functioning in an integrated manner with the environment (University of Johannesburg, 2017:4). A person, in this study, is referred to as parents and their adolescent with intellectual disability.

1.6.1.2 Mental health

Mental health is a dynamic interactive process in the parents' environment (University of Johannesburg, 2017:5). In this study, the mental health of the parents who have an adolescent with intellectual disability was considered by making recommendations to facilitate their mental health in view of the research findings.

1.6.1.3 Environment

The environment includes an internal and external environment. The internal environment consists of the dimensions of body, mind and spirit. The external environment consists of physical, social and spiritual dimensions (University of Johannesburg, 2017:5). In this study, the environment is the experiences that the parents have within and outside themselves regarding having an adolescent with intellectual disability.

1.6.1.4 Psychiatric nursing

Psychiatric nursing is an interactive process aimed at the facilitation and promotion of mental health (University of Johannesburg, 2017:5). Psychiatric nursing is the process whereby the psychological meaning of events, feelings and behaviours could be explored and incorporated into nursing intervention (Adams, 2017:10). In this study, the experiences of parents who have an adolescent with intellectual disability were explored in order to make recommendations for psychiatric nursing interventions to facilitate the parents' mental health.

1.6.2 Theoretical assumptions

A theory assists in examining, organising and representing facts (Mattson & Haas, 2014:13). Intellectual disability is considered a situated concept steeped in moral and cultural values and questions the scientific community's assertion that there exists a true or fixed definition of intellectual disability (Kamlager, 2013:28). Intellectual disability exists in the minds of those who use it as a term to describe the cognitive state of other people (Kamlager, 2013:28). The researcher chose to use the term

‘intellectual disability’ instead of ‘mental retardation’ as the latter appears to have a stigmatising effect on the people involved. The researcher next discusses the theoretical assumptions of concept clarification.

1.6.2.1 Conceptual framework

The researcher used the following concepts throughout the study: experiences, parents, adolescent, intellectual disability, which are defined in the sections that follow.

a) Definition of concepts

The researcher defines the concepts as follows:

a.i) Experience

Phenomenological studies examine human experiences through the descriptions that are provided by the people involved in answering the question posed to them (Creswell, 2014:56). In this phenomenological study, experience refers to the description of the meaning of experiences of parents who have an adolescent with intellectual disability.

a.ii) Intellectual disability

Intellectual disability, also known as a general learning disability and mental retardation, is a generalised neurodevelopmental disorder characterised by significantly impaired intellectual and adaptive functioning (Colin, 2013:1). It is defined by an Intelligence Quotient (IQ) score under 70, in addition to deficits in two or more adaptive behaviours including self-injury, stereotyped behaviour, aggression and destruction, that affect every day, general living (Colin, 2013:1). In this study, the researcher explored and described the experiences of parents who have an adolescent with intellectual disability in Giyani.

a.iii) Adolescent

An ‘adolescent’ refers to a young person in the process of developing from a child into an adult (Oxford Dictionaries, 2018:n.p.). In this study, an adolescent refers to any male or female person with intellectual disability from the ages of 15-17 years old.

a.iv) Parents

A ‘parent’ is defined as natural (biological) parents, whether they are married or not, and any person who, although not a natural parent, has parental responsibilities for a child or young person (Bedford Bough Council, 2018:n.p.). It is also any person who, although not a natural parent, has to care for a child or young person (Bedford Bough Council, 2018:n.p.). In this study, parents refer to the biological mother or father, or anybody who assumes that role, in caring for an adolescent with intellectual disability.

1.6.3 Methodological assumptions

Methodological assumptions consist of the assumptions made by the researcher regarding the methods used in the process of qualitative research. The researcher used inductive logic, studied the topic within its context, and then employed the emerging framework. The researcher worked with the data before generalising information (Creswell & Poth, 2018:1). Methodology is characterised by reflective analysis and the development of the way in which the researcher goes about theorising, observing, analysing, and interpreting (Lor, 2011:2).

The researcher used a constructivist worldview as constructivists believe that an individual seeks an understanding of the world in which they live and work. Individuals develop subjective meaning of their experiences and this led the researcher to look for the complexity of the view rather than the narrow meanings of a few categories or ideas (Creswell, 2014:8). The researcher’s goal was to rely as much as possible on the experiences of parents who have an adolescent with intellectual disability in Giyani.

In this study, the researcher used a qualitative, exploratory, descriptive and contextual design to enable the participants to express their experiences of having an adolescent with intellectual disability. Measures to ensure trustworthiness were applied throughout the research process.

1.7 RESEARCH DESIGN AND METHOD

The researcher used the qualitative research approach to explore and describe the experiences of parents who have an adolescent with intellectual disability in Giyani (Creswell & Poth, 2018:4). The research design and method are discussed next.

1.7.1 Research design

In this study, a qualitative, exploratory, descriptive and contextual design was applied (Creswell, 2014:4) in order to capture the essence of the experiences of parents who have an adolescent with intellectual disability. Qualitative research was conducted to gain and discover meaning about the experiences of parents who have an adolescent with intellectual disability.

Researchers use qualitative approaches to explore the behaviours, feelings and experiences of people and what lies at the core of their lives (Holloway & Galvin, 2017:3). The intent is an in-depth understanding of a selected sample that meets the criteria set by the researcher (Gray, Grove & Sutherland, 2017:344). The researcher focused on the way in which the parents made sense of their experiences and the world in which they live, with the aim of understanding, describing and interpreting their experiences as perceived by individual parents who have an adolescent with intellectual disability. The research design is discussed in-depth in Chapter 2.

1.7.2 Research method

The study was conducted in two phases. In Phase 1, the researcher explored and described the experiences of parents who have an adolescent with intellectual disability in Giyani. In Phase 2, the researcher developed recommendations to

facilitates the mental health of parents who have an adolescent with intellectual disability.

1.7.2.1 Phase 1: Exploration and description of the experiences of parents who have an adolescent with intellectual disability

In this study, descriptive phenomenology was utilised as the researcher described the experiences of parents who have an adolescent with intellectual disability. The researcher bracketed or put aside her own preconceived opinions according to Husserl's descriptive phenomenological research approach (Reiners, 2012:119). The researcher explored and described the experiences of parents who have an adolescent with intellectual disability in Giyani by engaging in the following aspects:

a) Population and Sample

Rebar and Gersch (2015:110) describe the population as the entire group of individuals about whom the researcher is interested in gaining knowledge. The population of this study was parents who have an adolescent with intellectual disability. The adolescents with intellectual disability had to have been admitted to a psychiatric hospital. The researcher selected a portion of the population referred to as the sample. A sample is a subset of the total group of interest in a study (Rebar & Gersch, 2015: 31).

A purposive sampling method was used in this study, which is also known as purposeful, judgemental or selective sampling since it entails making a judgement about the population to be studied (Gray, et al. 2017:345). The researcher focused on gaining insight, descriptions and understanding of the experiences of parents who have an adolescent with intellectual disability (Gray, et al. 2017:337).

Participants had to meet the following inclusion criteria for this study:

- Parents could be either a male or female parent
- Parents had to have an adolescent who has intellectual disability

- The adolescent with intellectual disability had to be admitted to a psychiatric hospital
- The adolescent was between the age of 15 to 17 years
- Participants preferably had to be able to communicate in English, Xitsonga, Sepedi or Tshivenda

b) Data collection

During data collection, the researcher utilised phenomenological, in-depth interviews to explore and describe the experiences of parents who have an adolescent with intellectual disability and used bracketing to avoid bias. In the study, the researcher asked one main, open-ended question to the participants:

"How is it to have an adolescent with intellectual disability?"

Observations and field notes were also used for data collection (Holloway & Galvin, 2017:3-11). The interviews lasted 40-60 minutes, and the researcher's responses were minimal to give participants more time to express their views.

The researcher, in an observational role, assumed the role of an 'inside' observer who actually engaged in activities in the study site. It is difficult to take notes while participating, and the researcher needed to wait until after she left the research site to write down her observations (Creswell, 2012:214).

c) Data analysis

Data analysis include both the coding and the thought processes that go behind assigning meaning to data. The researcher sought meaning from all of the raw data that were analysed. The researcher used Tesch's method of thematic data analysis (Creswell & Poth, 2018:196) to analyse and make sense of data that were collected. Units of meaning were identified from the data, and transcribed interviews and field notes were linked together to form themes with supporting categories. An independent coder who is experienced in qualitative research then analysed the data. The

researcher and the independent coder met for a consensus discussion on the results of the data analysis.

d) Literature control

The researcher used literature to justify the need for the study. The literature was also useful in supporting or modifying existing findings in the literature in order to show the positive or negative implications of the findings in relation to the experiences of parents who have an adolescent with intellectual disability in Giyani.

1.7.2.2 Phase 2: Recommendations to facilitate the mental health of parents who have an adolescent with intellectual disability

These recommendations were generated based on the results that were derived from Phase 1. It included a description of how the mental health of parents who have an adolescent with intellectual disability could be facilitated.

1.8 MEASURES TO ENSURE TRUSTWORTHINESS

The researcher ensured the trustworthiness of the study by applying the measures of credibility, transferability, dependability and confirmability.

1.8.1 Credibility

Credibility focuses on whether the results accurately represent the underlying meaning of data, and it is improved by prolonged engagement in the data collection process and triangulation (Houser, 2012:425). Credibility means that the participants recognise the meaning that they themselves give to a situation, or the condition and 'truth' of the findings in their own social context (Holloway & Wheeler, 2010:54). In this study, the researcher used prolonged engagement, a reflective diary, peer evaluation, member checking and in-depth interviews to ensure the credibility of the study.

1.8.2 Transferability

Lincoln and Guba (1985:327) use the term ‘transferability’ instead of ‘generalisation’, which means that the findings in one context can be transferred to similar situations or participants. Lincoln and Guba (1985:327) further describe transferability as the extent to which the findings of a study are confirmed by or applicable to a different group in a different setting from where data were collected (Rebar & Gersch, 2015:155). A dense description was made of the demographics of the participants. A rich description of the results with supporting direct quotations from the participants are also presented.

1.8.3 Dependability

In qualitative research, consistency is defined in terms of dependability. Dependability refers to the provision of evidence such that if it were to be repeated with the same or similar participants in the same or similar context, the findings would be similar (Holloway & Wheeler, 2010:55). Lincoln and Guba (1985:327) use the term ‘dependability’ instead of ‘reliability’, which means that the findings of the study should be consistent and accurate to establish the trustworthiness of the study (Holloway & Wheeler, 2010:55). Therefore, a dense description of the research methodology was given.

1.8.4 Confirmability

Lincoln and Guba (1985:327) state that ‘confirmability’ means that an audit or decision trail is necessary where readers can trace data to their sources. When confirmability exists, readers can trace data to their original source (Holloway & Wheeler, 2010:55). There should be an internal agreement between the researcher’s interpretation and the actual evidence. This is accomplished by incorporating an audit procedure. An audit was done of the whole research process to ensure confirmability. Lincoln and Guba (1985:327) describe ‘confirmability’ as the consistency and repeatability of decision making about the process of data collection and data analysis (Rebar & Gersch, 2015:154).

The measures to ensure trustworthiness are discussed in-depth in Chapter 2.

1.9 ETHICAL CONSIDERATIONS

Ethical principles of autonomy, beneficence, non-maleficence and justice (Dhai & McQuoid-Mason, 2011:14-15) were applied throughout the study.

1.9.1 Principle of autonomy

Autonomy means that participants must be allowed to make a free, independent choice to participate in the study. Autonomy underpins the notion of informed consent and refusal (Holloway & Wheeler, 2010:30). Participants have the right to self-determination, meaning that the participants are autonomous and have the right to make a knowledgeable decision that is free from coercion as to whether or not to participate in research or to withdraw from a study (Rebar & Gersch, 2015:136).

According to Dhai and McQuoid-Mason (2011:14-15), the researcher has a responsibility to ensure that participants in the study are not unduly influenced to participate. In this study, the researcher ensured that the participants fully understood what informed consent entails for them to make an informed decision (See Annexure F). The participants determined the time and place where the interviews were held with the researcher. The participants were informed that the researcher would provide each participant with a number or code, or that they could devise their own codes to ensure that their identities are not recognised and kept anonymous. The list of real names was destroyed after data analysis was completed. The researcher will keep the matching code numbers in a safe place, and the data will be destroyed two years after the publication of the research.

1.9.2 The principle of beneficence and non-maleficence

The principle of beneficence and non-maleficence states that the benefits of participating in a study should outweigh the risk for the individual and wider society (Holloway & Wheeler, 2010:303). It is up to the researcher to weigh the risks and the benefits associated with participating in the study, and it is up to the participants to

decide whether to participate in the study. Therefore, the researcher ensured that during this study the participants were protected against any kind of harm and the potential risk to the participant's psychological well-being, mental health, personal values and dignity were considered. The participants were not exposed to any risks greater than or additional to those which they are exposed to in their everyday life. The risk-benefit ratio was discussed with the participants. There were no direct benefits for participants.

1.9.3 Principle of justice

Justice means that all people should be treated equally (Flick, 2014:51). Individuals have the right to fair treatment. Rebar and Gersch (2015:136) state that individuals have the right to non-discriminatory selection to be participants. The participants of this study were treated with fairness at all times; the researcher made sure that all participants were respected and treated equally. The researcher selected the participants for reasons directly related to the research problem and not because they were readily available or could be easily manipulated (Dhai & McQuoid-Mason, 2011:15). All participants had time to ask questions relating to the study.

1.10 CONCLUSION, LIMITATIONS AND RECOMMENDATIONS

Limitations are aspects related to how the researcher created uncertainty concerning the conclusions that were derived from a study, as well as the decisions that were based on it (Rebar & Gersch, 2015:32). Limitations, recommendations and conclusion are discussed in detail at the end of the study with reference to the research findings.

1.11 DIVISION OF CHAPTERS

This study is divided into four chapters:

Chapter 1: Introduction, Rationale and Overview
Chapter 2: Research Design and Method
Chapter 3: Results: The Experiences of Parents who have an Adolescent with Intellectual Disability in Giyani

Chapter 4: Limitations, Recommendations and Conclusions

1.12 SUMMARY

The purpose of this study was to describe the experiences of parents who have an adolescent with intellectual disability in Giyani, and to develop recommendations to facilitate these parents' mental health.

Paradigmatic perspectives were discussed under the meta-, theoretical and methodological assumptions of the Theory for Health Promotion in Nursing (University of Johannesburg, 2017:5). The theoretical assumptions were explained through the definition of concepts. A qualitative, exploratory, descriptive, contextual design was used in this study. The research method consisted of two phases. Phase 1 explored and described the experiences of parents who have an adolescent with intellectual disability, and in Phase 2 the researcher developed recommendations to facilitate the mental health of parents who have an adolescent with intellectual disability.

The researcher explained how she ensured the trustworthiness of the study through credibility, transferability, dependability and confirmability. The researcher also considered the ethical principles, such as the principles of autonomy, beneficence, non-maleficence and justice. The research design and method are discussed in detail in Chapter 2.

CHAPTER 2
RESEARCH DESIGN AND METHOD

2.1 INTRODUCTION

The researcher chose a qualitative approach as it was suitable for this study which explored and described the experiences of parents who have an adolescent with intellectual disability. In this chapter, the research design and method, measures to ensure trustworthiness and ethical principles that were applied in this study are discussed.

2.2 RESEARCH PURPOSE AND OBJECTIVES

The purpose and objectives were discussed as follow:

2.2.1 Research purpose

The purpose of this study was to describe the experiences of parents who have an adolescent with intellectual disability in Giyani, and to develop recommendations to facilitate these parents' mental health.

2.2.2 Research objectives

The objectives of this study were:

- To explore and describe the experiences of parents who have an adolescent with intellectual disability in Giyani.
- To describe recommendations for the facilitation of the mental health of parents who have an adolescent with intellectual disability in Giyani.

2.3 RESEARCH DESIGN AND METHOD

In the research design, the researcher discusses the qualitative approach under the following designs: qualitative, exploratory, descriptive and contextual research designs.

2.3.1 Research design

In this study, a qualitative, exploratory, descriptive, contextual design was utilised (Creswell, 2014:187) in order to capture the essence of the experiences of parents who have an adolescent with intellectual disability. Qualitative research was conducted to gain insight and discover meaning about the experiences of these parents.

2.3.1.1 Qualitative research design

A qualitative design is an approach to research that focuses on understanding the complexity of humans within the context of their lives (Rebar & Gersch, 2015:35). In this study, the focus was on building a picture of the experiences of parents who have an adolescent with intellectual disability in Giyani. It involved the collection of information as it is expressed naturally by those parents who have an adolescent with intellectual disability within the normal context of their lives. The researcher used a qualitative design to explore and describe the experiences of these parents.

2.3.1.2 Exploratory research design

The researcher used an exploratory design to explore and describe the experiences of parents who have an adolescent with intellectual disability (Creswell, 2014:4). The researcher employed questions that were open-ended and nonthreatening, determining participants' perspectives.

2.3.1.3 Descriptive research design

A descriptive design is a research design that functions to portray some phenomenon of interest as accurately as possible (Gray, et al. 2017:278). The parents who have an adolescent with intellectual disability described their experiences as they viewed and lived it. Follow-up questions were asked (Gray, et al. 2017:278). The researcher asked nonthreatening, thought-provoking questions to encourage the participants to describe their experiences of having an adolescent with intellectual disability.

2.3.1.4 Contextual research design

The researcher was sensitive to the context of the research and immersed in the setting and situation (Holloway & Galvin, 2017:4). The context of this study was the homes of parents who have an adolescent with intellectual disability in Giyani. The data collected were contextualised into the current research literature on parents' experiences of having an adolescent with intellectual disability.

2.3.2 Research method

The research took place in two phases: In Phase 1, the researcher explored and described the experiences of parents who have an adolescent with intellectual disability, and in Phase 2, the researcher developed recommendations to facilitate the mental health of parents who have an adolescent with intellectual disability. The phases are discussed next.

2.3.2.1 Phase 1: Exploration and description of the experiences of parents who have an adolescent with intellectual disability

In this study, a descriptive phenomenological approach was utilised as the parents described their experiences of having an adolescent with intellectual disability. The researcher employed bracketing; that is, she put aside her own preconceived opinions according to Husserl's descriptive phenomenological research (Reiners, 2012:119).

a) Population and sampling

Rebar and Gersch (2015:110) describe the population as the entire group of individuals about whom the researcher is interested in gaining knowledge. The population of this study was parents who have an adolescent with intellectual disability in Giyani. The adolescents with intellectual disability were admitted to a psychiatric hospital. The researcher selected a portion of a population referred to as the sample. A sample is the subset of the total group of interest in a study (Rebar & Gersch, 2015:31), that is, parents who have an adolescent with intellectual disability.

A purposive sampling method was used in this study, which is also known as 'judgmental' sampling since it entails making a judgment about the population to be studied (Gray, et al. 2017:345). In this study, the participants were parents who have an adolescent with intellectual disability.

The size of the sample depended on the saturation of data, where no new ideas or information were shared by the participants (Gray, et al. 2017:352). The researcher justified the adequacy of the sample size and the number of participants in the study based on saturation; additional sampling provided no new information, only redundancy of previously collected data (Gray, et al. 2017:352).

Participants met the following inclusion criteria:

- Parents could be either a male or female parent
- Parents had to have an adolescent who has intellectual disability
- The adolescent with intellectual disability had to be admitted to a psychiatric hospital
- The adolescent was between the age of 15 to 17 years
- Participants preferably had to be able to communicate in English, Xitsonga, Sepedi or Tshivenda.

b) Role of a researcher

The researcher conducted the following process while collecting data:

b.i) Bracketing

The researcher identified, documented and chose to set aside her own opinions on the experiences of parents who have an adolescent with intellectual disability. Bracketing required the researcher to acknowledge any previous knowledge, ideas, or beliefs about the experiences of parents who have an adolescent with intellectual disability (Gray, et al. 2017:275).

b.ii) Intuiting

Intuition means the researcher is immersed in the description of the lived experience (Rebar & Gersch, 2015:183). The researcher focused all her awareness and energy on the experiences of parents who have an adolescent with intellectual disability.

b.iii) Communication techniques

The researcher asked open-ended questions, allowing the participants to respond freely to questions by asking nonthreatening questions. The researcher also kept her input to a minimal to give the participants an opportunity to express themselves. She responded by showing interest and concern, and nodding as the participants were explaining their experiences. On the other hand, the researcher also observed nonverbal communication in the field of the study (Gray, et al. 2017:256), like participants' facial expressions.

c) Research setting

The researcher collected data in the field at the site where participants experienced the issue or problem that was being studied (Creswell, 2014:185). The researcher works at a psychiatric hospital in the unit where adolescents with intellectual disability

are admitted in Giyani. The researcher requested permission to undertake the study from the hospital manager.

The unit manager of the mental health ward identified participants as parents of adolescents with intellectual disability whose children were admitted to that specific ward. The unit manager was requested to contact the parents of adolescents with intellectual disability and to invite them to take part in the study. After parents agreed to participate in the study, their contact information was provided to the researcher. The researcher contacted the parents and arranged to interview them. The interviews took place at the homes of the parents who have an adolescent with intellectual disability.

d) Data collection

During data collection, the researcher utilised phenomenological, in-depth interviews to explore and describe the experiences of parents who have an adolescent with intellectual disability. Bracketing was also used to avoid bias in the study, as well as observations and field notes (Holloway & Galvin, 2017:3-11). The methods of data collection are discussed as follows:

d.i) In-depth phenomenological interviews

In-depth phenomenological interviews are a qualitative method used to discover and develop an understanding of experiences as perceived by those living the experience (Rebar & Gersch, 2015:183). Gray, et al. (2017:259) describe in-depth interviews as informal and conversational interaction between the researcher and the participant.

The researcher sought information through in-depth, phenomenological interviews exploring the experiences of parents who have an adolescent with intellectual disability. The researcher requested to visit the participants at their homes for the interviews, where face-to-face interaction took place. The interview sessions lasted 40-60 minutes and were audio-recorded and transcribed before being analysed.

In the study, the researcher asked one main question to the participants. The question was:

"How is it to have an adolescent with intellectual disability?"

Follow-up questions, probing and minimal verbal responses were used only to confirm or look for the underlying meaning of the statements given by the participants (De Vos, Strydom, Fouché & Delport, 2011:345). As data were being collected, the researcher used the processes of intuiting, analysing and describing to discover essential themes in the experiences of parents who have an adolescent with intellectual disability.

The researcher stopped collecting data when enough rich, meaningful data had been obtained to achieve the objectives of the study, which is called data saturation. Gray, et al. (2017:255) define 'data saturation' as the point at which new data become redundant with what has already been found and no new themes can be identified.

d.ii) Observation and Fieldnotes

The researcher used in-depth interviews that included the actual words of the participants, and field notes. These notes are often called observational notes because they are a record of the researcher's observations about the overall setting and experience of the data collection process while in the setting or field (Rebar & Gersch, 2015:152). Methodological notes were taken during data collection. The researcher also used personal notes in which she observed and thought about the underlying meaning of what she observed, and recorded her thoughts and ideas accordingly.

d.iii) Role of the researcher as an observer

The researcher assumed the role of an observer who actually engaged in activities in the study site. It was difficult to take notes while participating, and the researcher needed to wait to write down her observations until after she had left the research site (Creswell, 2014:190). Gray, et al. (2017:156) state that even when other data collection methods are being used, such as interviews, the researcher must be aware

of the surroundings and attend to the communication that occurs between the participants and other immediate surroundings. The researcher also collected data through listening, smelling, touching, and seeing, with the emphasis on what was seen.

e) Data analysis

Data analysis included both the coding and the thought processes that went behind assigning meaning to data. The researcher used Tesch's method of thematic data analysis (Creswell, 2014:196) to analyse and make sense of data that were collected. An independent coder who is an expert in qualitative research then analysed data separately from the researcher. The researcher and the independent coder met for a consensus discussion on the results of the data analysis.

The steps used in data analysis included:

Step 1: Transcribe all the data. The interviews were transcribed, and field notes were typed up.

Step 2: Organise and prepare data for analysis. Data were sorted and arranged into different types depending on the sources of information (Creswell, 2014:197). The researcher sought meaning from all of the raw data that were available to analyse.

Step 3: Read and look at all the data. The data were read, and the researcher analysed what the participants were saying, the tone of the ideas, the overall depth, credibility, and use of the information (Creswell, 2014:197). The researcher read data to reflect on the overall meaning.

Step 4: Coding all the data. Coding is the process of organising the data by bracketing chunks (Creswell, 2014:197). As the volume of data acquired in the study was significant, the researcher focused on reducing the volume so that she could examine the data more effectively using the coding method. As the researcher was reducing the volume of the data, she attached meaning to the elements in the data and documented the meaning with a word, symbol, or phrase. Gray, et al. (2017:270)

describe coding as a means of naming, labelling, and later sorting data elements, which allows the researcher to relate themes and patterns.

Step 5: Use the coding process to generate a description of the setting or people as well as categories or themes for analysis. Units of meaning were identified from the data, transcribed interviews and field notes, which were linked together to form themes with supporting categories. Themes are patterns in the data or ideas that are repeated by more than one participant (Gray, et al. 2017:251). As themes were identified, the researcher used deductive reasoning when considering the fit of the data to the themes.

Step 6: Establish how the themes will be represented to convey the findings of the analysis.

Step 7: Interpretation of qualitative research findings or results. After interrelating the themes and patterns, the researcher interpreted the meaning of themes. Interpretation is translating the words and actions of participants into meanings that readers and consumers can understand (Gray, et al. 2017:269).

Step 8: Generalisation of the data. Small sets of generalisations were elaborated and examined in light of the formalised body of knowledge.

f) Literature control

The researcher used the literature to justify the need for the study. It also assisted her to support or modify existing findings in the literature in order to show the positive or negative implications of the findings in relation to the experiences of parents who have an adolescent with intellectual disability.

2.3.2.2 Phase 2: Recommendations to facilitate the mental health of parents who have an adolescent with intellectual disability

Recommendations to facilitate the mental health of parents who have an adolescent with intellectual disability were developed after the data were analysed and the

researcher had attached meanings to the collected data. Recommendations were formulated in view of the research findings.

2.4 MEASURES TO ENSURE TRUSTWORTHINESS

Table 2.1 presents an overview of measures to ensure trustworthiness observed in this study.

Table 2.1: Measures to ensure trustworthiness

MEASURES	METHODS
Credibility	*Prolonged engagement with the field* *Reflexivity* *Persistent observations* *Triangulation* *Peer review* *Member checking* *In-depth interviews* *Structural coherence*
Transferability	*Purposive sample* *Dense description of demographics of participants* *Rich description of results supported by direct quotations from the participants*
Dependability	*Dense description of research methodology* *Stepwise replication of research* *Code-recode procedure*
Confirmability	*Audit trail* *Chain of evidence*

The researcher ensured the trustworthiness of the study by applying the following measures:

2.4.1 Credibility

Credibility means that the participants recognise the meaning that they give to a situation or condition and the truth of the findings in their own social context (Holloway & Wheeler, 2010:54). Credibility was ensured since the results accurately represent the underlying meaning of data, and it was improved by prolonged engagement in the data collection process and triangulation (Houser, 2012:425). In this study, the researcher made use of prolonged engagement, a reflective diary, peer evaluation, member checking and in-depth interviews to ensure the credibility of the study. The methods to ensure the credibility of the study are discussed as follows:

2.4.1.1 Prolonged engagement

The researcher became closely involved in the participants' experiences to interpret it by making the participants feel safe and able to trust the researcher prior to sharing their deepest experiences with her. The researcher was open to the participants' perceptions rather than attaching her own meaning to their experiences (Gray, et al. 2017:256).

2.4.1.2 Reflexivity

Gray, et al. (2017:256) describe reflexivity as the ability to be aware of the researcher's own bias or past experiences that might influence how the researcher would respond to participants or interpret data. The researcher had to be aware of her personal experiences and potential bias related to the experiences of parents who have an adolescent with intellectual disability. She documented these experiences and potential bias before and during the study in the reflective journal, to be aware of them during data analysis.

2.4.1.3 Persistent observations

The researcher noted relevant observations in the research setting. The participants' nonverbal responses, their reactions, as well as their expressions, actions and tone of

voice, were noted and clarified as another form of data collection (Rebar & Gersch, 2015:152).

2.4.1.4 Triangulation

Lincoln and Guba (1985:327) describe triangulation as the process of using more than one approach or source to be included in different views or to look at the phenomenon from different angles (Rebar & Gersch, 2015:156). The researcher focused on the data, seeking different types of information regarding the experiences of parents who have an adolescent with intellectual disability. The researcher used in-depth phenomenological interviews, observation and field notes.

2.4.1.5 Peer review

Rebar and Gersch (2015:207) describe the peer review as the manuscript for the published report having been read and critiqued by two or more peers before being accepted for publication. The peer review helped in ensuring the credibility of the study.

The researcher allowed the manuscript of the study to be scrutinised by peers for quality before handing it over for publication acceptance.

2.4.1.6 Member checks

Member checking is when data and findings from data analysis are brought back to the original participants to seek their input concerning the accuracy, completeness and interpretation of the data (Rebar & Gersch, 2015:156). The researcher sought feedback from participants whose experiences differed from those already included in the study. The researcher also used member checks to ensure the credibility of the study. Member checking was done by returning the transcripts to the participants for them to confirm if it was what they meant in their interviews. Some participants agreed with the transcriptions, and some add more information into the transcribed data.

2.4.1.7 In-depth interviews

In this study, individual, in-depth, phenomenological interviews were employed in order to produce dense and quality information of the phenomenon under study.

2.4.1.8 Flexibility

Flexibility was allowed through achieving the goal of describing and understanding participant perspectives, qualitative methods of sampling, data gathering, and analysis (Gray, et al. 2017:251). The researcher was flexible in the questions she asked to ensure participants understand them. She ensured their understanding through paraphrasing and asking for clarity so that she could get a clear picture of the participants' experiences.

2.4.2 Transferability

Lincoln and Guba (1985:327) use the term 'transferability' instead of generalisation, which means that the findings in one context can be transferred to similar situations or participants (Holloway & Wheeler, 2011:55). Lincoln and Guba (1985:327) further describe transferability as the extent to which the findings of a study are confirmed by or are applicable to a different group in a different setting from where data were collected (Rebar & Gersch, 2015:155). Methods used to ensure the transferability of the study are described next.

2.4.2.1 Purposive sampling

Purposive sampling helped the researcher focus on the key informants, who were particularly knowledgeable of the issue under investigation because purposive sampling allows decisions to be made about the selection of participants. It allowed the researcher to decide why she wanted to use a specific category of informants in the study, and it provided greater depth of findings (Scholarlink Research Institute, 2014:278).

2.4.2.2 Dense description

A dense description was made of the demographics of the participants.

2.4.2.3 Rich description

A rich description of the results, with supporting direct quotations from the participants, was presented.

2.4.3 Dependability

Dependability refers to the provision of evidence; if the study were to be repeated with the same or similar participants in the same or similar context, its findings would be similar (Holloway & Wheeler, 2011:55). Lincoln and Guba (1985:327) use the term 'dependability' instead of reliability, which means that the findings of the study should be consistent and accurate to establish the trustworthiness of the study (Holloway & Wheeler, 2010:55). The methods to achieve dependability are discussed next.

2.4.3.1 Dense description of the research methodology

A dense description of the research methodology was given. The researcher ensured the dependability of the study by maintaining the in-depth description of the research methodology.

2.4.3.2 Stepwise replication of research

Stepwise replication is a qualitative data evaluation procedure where two or more researchers analyse the same data separately and compare the results. In this study, any inconsistencies that arose from these separate analyses needed to be addressed to improve the dependability of the inquiry. If the results are similar, then dependability of the inquiry is achieved (Scholarlink Research Institute, 2014:278).

2.4.3.2 Code-recode strategy

The code-recode strategy involves the researcher coding the same data twice, giving one- or two-weeks' gestation period between each coding. The results from the two codings were compared to see if the results were the same or different. It helped the researcher to gain a deep understanding of data patterns and improved the presentation of participants' narrations (Scholarlink Research Institute, 2014:278).

2.4.4 Confirmability

Lincoln and Guba (1985:327) state that 'confirmability' is an audit or decision trail where readers can trace data to their sources. Lincoln and Guba (1985:327) describe confirmability as the consistency and repeatability of decision making about the process of data collection and data analysis (Rebar & Gersch, 2015:154).

When confirmability exists, readers can trace data to their original source (Holloway & Wheeler, 2010:55). There should be internal agreement between the researcher's interpretation and the actual evidence. This was accomplished by incorporating an audit procedure. The audit was done throughout the whole research process to ensure confirmability.

The researcher kept all documentation on her decisions about the data analysis and collection process. This method is called an audit trail. Documentation from the audit trail included field notes about the collected data, ideas developed during the analysis, or notes regarding approaches to categorise or organise the data. The researcher used an audit trail to be consistent and to demonstrate the presence of consistency when sharing the data. A chain of evidence was achieved through triangulation.

2.5 ETHICAL CONSIDERATIONS

The researcher had an obligation to protect the privacy of the participants and to protect the participants from the risk of significant harm. It was important to obtain consent from the participants after providing them with a full explanation of the study. Participants were entitled to withdraw from the study at any point without penalty

(Ingham-Broomfield, 2016:35). Informed consent is the legal principle that a participant can make decisions about their participation in a research study only after receiving all relevant information pertaining to the study, as well as being given a reasonable amount of time to consider the decision to participate (Rebar & Gersch, 2015:137). In this study, the researcher applied the principles of autonomy, beneficence, maleficence and justice, which were discussed in Chapter 1.

2.6 SUMMARY

In this chapter, the researcher presented how the study was executed. The purpose and objectives of the study were identified. The researcher also discussed the qualitative approach under the exploratory, descriptive and contextual research design which was the research design employed in this study. The population and sampling were indicated along with measures to ensure the trustworthiness of the study.

In Chapter 3, a discussion of findings and literature control is presented.

CHAPTER 3
RESULTS: THE EXPERIENCES OF PARENTS WHO HAVE AN ADOLESCENT WITH INTELLECTUAL DISABILITY IN GIYANI

3.1 INTRODUCTION

Interviews were conducted according to the research design, which was introduced in Chapter 1 and described in Chapter 2. The experiences of parents who have an adolescent with intellectual disability are described in this chapter. The discussion of these parents' experiences includes their direct quotations. The discussion is thus based on transcribed interviews and field notes.

3.2 DEMOGRAPHIC PROFILE OF PARTICIPANTS

Eight parents of adolescents with intellectual disability in Giyani were interviewed.

As specified, in this study the term 'parents' refers to the biological mother or father or anybody who assumes that role in caring for an adolescent with intellectual disability. The majority of the families were from low-income status. Some adolescents were cared for by a grandmother, aunt or sibling because their biological parent had passed away, but a few still had their biological parents. Two of the participants were the adolescents' grandmothers, four were biological mothers, one was an aunt, and one was a sister. Some lived in the Reconstruction and Development Programme (RDP) houses, some were living in a two-roomed house, while for others the environment was not conducive due to overcrowding. Two of the families had decent housing. The participants' demographics are presented in Table 3.1.

Table 3.1: Demographics of participants

Part. no	Age	Gender	Relationship	Socio-economic status	Housing	Years looking after adolescent
1	57yrs	Female	Grandmother	Domestic worker	RDP house	15 years
2	51yrs	Female	Aunt	Unemployed	Four-roomed house	04 years

Part. no	Age	Gender	Relationship	Socio-economic status	Housing	Years looking after adolescent
3	64yrs	Female	Mother	Pensioner	Two-roomed house	17 years
4	55yrs	Female	Mother	Domestic worker	Cracked three-roomed house	17 years
5	34yrs	Female	Sister	Casual employee	RDP house	10 years
6	48yrs	Female	Mother	Casual employee	Four-roomed house	16 years
7	46yrs	Female	Mother	Employed	Five-roomed house	17 years
8	76yrs	Female	Grandmother	Pensioner	RDP house	17 years

3.3 DATA COLLECTION AND ANALYSIS

Data collection took place from November 2018 to January 2019. The interviews were conducted at the homes of the participants, after making an arrangement of time and date that suited them. The main question asked to the participants was:

"How is it to have an adolescent with intellectual disability?"

Field notes were written during and after the interviews. Participants preferred to be interviewed in their home language, therefore the interviews were conducted in Xitsonga. The direct quotations were translated into English for those who would not be able to read or understand Xitsonga.

3.4 RESEARCHER'S EXPERIENCE

The researcher was touched emotionally by what the participants were experiencing, as the participants were also emotional. The researcher was of the opinion that she could perhaps do something to help these families. The parents at first seemed to be nervous, but during the interview process, it appeared as if they had been waiting a

long time to express themselves. Even though their situation was touching, the researcher remained in control and objective in the study.

3.5 DISCUSSION OF THE FINDINGS AND LITERATURE CONTROL

The discussion of findings of the experiences of parents who have an adolescent with intellectual disability in Giyani is presented in an essay format based on the outline presented in Table 3.2. The discussion was guided by the themes and categories in this chapter, as discussed in the central storyline. The direct quotations from participants were used as supporting evidence of the findings, along with a literature control in order to show the implications of the findings in relation to the experiences of parents who have an adolescent with intellectual disability.

3.5.1 Central storyline

Parents who have an adolescent with intellectual disability faced challenges. The main challenge was stress, and the themes that were developed emanated from the stress the parents were experiencing.

Parents had emotional responses that were manifested by being sad, distressed, worrying, being fearful of death and the future, and feeling that they were neglecting other family members. They also experienced a lack of support. Most participants complained of being neglected by family members and abandoned by their husbands because of the adolescent with intellectual disability, social isolation and stigma. However, some parents did have support from their family members, employers, and community members, and all parents got some support from the government services as the adolescents were admitted to a government hospital. They experienced caring challenges as some of the adolescents were aggressive and destructive, and some were difficult to manage due to their physical body deformity and behaviour, which was distressing to the parents. These caring challenges ranged from physical frailty, difficulties in managing the adolescent, and poverty, as they had financial constraints and inadequate living environments. Generally, they coped positively by putting their faith in God and accepting their situation.

The parents of adolescents with intellectual disability were relieved when their adolescents were admitted to the psychiatric hospital. The burden of caring for the adolescents was partially shifted as some participants were working and others had to care for other siblings who were ill. Some participants were too old to take care of the adolescent with intellectual disability and had physical frailty.

Some parents explained that in order for them to care for their adolescents full-time, they had to leave their jobs and stay at home. They could not afford to hire a nanny. Some parents were domestic workers, some casual workers, and others were pensioners. One was an administrative clerk.

Table 3.2: Themes and categories of the experiences of parents who have an adolescent with intellectual disability

THEMES	CATEGORIES
3.1.1 Theme 1: Emotional responses experienced by parents who have an adolescent with intellectual disability	**a) Sadness experienced by parents who have an adolescent with intellectual disability** **b) Worry, fear of death and the future experienced by parents who have an adolescent with intellectual disability** **c) Distress experienced by parents who have an adolescent with intellectual disability** **d) Experienced feelings that parents were neglecting other family members**
3.1.2 Theme 2: Experiences of support by parents who have an adolescent with intellectual disability	**a) Experienced a lack of support by parents who have an adolescent with intellectual disability in terms of** i) Experienced neglect from family members and the community

THEMES	CATEGORIES
	ii) Experienced rejection from their husbands iii) Experienced social isolation iv) Experienced stigma **b) Experienced an abundance of support by parents who have an adolescent with intellectual disability** i) Experienced support from family members ii) Experienced support from employers iii) Experienced support from community members iv) Experienced support from government services
3.1.3 Theme 3: Caring challenges experienced by parents who have an adolescent with intellectual disability	**a) Experienced physical frailty** **b) Experienced difficulties in managing the adolescent** **c) Experienced a lack of physical resources** **d) Experienced poverty** i) Experienced financial difficulties ii) Experienced inadequate housing
3.1.4 Theme 4: Positive coping mechanisms experienced by parents who have an adolescent with intellectual disability	**a) Experienced positive coping through their faith in God** **b) Experienced positive coping through acceptance**

3.5.1.1 Theme 1: Emotional responses experienced by parents who have an adolescent with intellectual disability

To raise an adolescent with intellectual disability was stressful to parents. Participants explained how hard it was to have an adolescent with intellectual disabilitiy. Some participants shared that they took over the caring role as the biological parents had passed away – some due to a stroke as a result of stress, others were stroke survivors, and a few were just physically frail. Another parent explained that she was so stressed about her child's condition that she ended up having high blood pressure and then became a chronic patient. Most participants complained of being stressed by the adolescents' condition because they require more time of care. When parents were interviewed, it was discovered that they had developed emotional responses, which included sadness, worry, fear of death and the future, distress, and feelings that they were neglecting other family members. These emotional responses are discussed as follows:

a) Sadness experienced by parents who have an adolescent with intellectual disability

Sadness is the state of feeling unhappy. Of course, one can feel unhappy when faced with challenging situations. Most parents experienced sadness because of the challenges they experienced due to having an adolescent with intellectual disability. They were emotional and tearful during interviews and looked sad when sharing their experiences. They could hardly look at the researcher as they were relating their stories. Some of the biological parents had passed away, thus their sibling and a grandmother had to take over, and were left to tell the story.

Some explained that they became tearful when they visited the adolescent at the hospital and after the visit. They said:

> *"Marha hi minkari yo tala loko ni fika ni rhanga hi ku fika ni rhanga ni thonisa mihloti, ene loko ni thonisa mihloti, u sungula ku visingana na yena."* But most of the time when I visit her, I cry when I see her, and

when she sees me cry, she will also become sad. (Participant 1, 57 yrs, grandmother)

"Loko swin'wani swi nga fambi kahle, i tshama hansi i rila, ita byela mani. Loko swin'wani swi nga fambi kahle i tshama hansi i rila. Nkarhi wun'wana wa tshama hansi i rila uri one. Se hala i ta ku wena i rila hiku vatswari i hava, hala i na makwenu wa disable, hala swa whe aswi fambi straight." When something doesn't go well, I sit down and cry alone, who shall I tell. When something doesn't go well, I sit down and cry. While crying that I have no parents, on one side my sibling has disability, on the other side nothing is working out for me. (Participant 5, 34 yrs, sister)

Continuous sadness could change the mental health of some parents who have an adolescent with intellectual disability. One of the parents explained how her mental health was altered:

"Se ti problem ta mhi tindli ku na mbilu yi va tani. Aya hari kahle. Imm, yi so, yi tsinini swinene, ma swivona." So my problems made me have a short temper. I'm no longer the same old person. Emm, it is like that, my patience is so short. (Participant 7, 46 yrs, mother)

Some literature highlighted that expectations often turn to some level of disappointment if a child has an impairment, as communities perceive a child with impairments as being cursed by God (Taderera & Hall, 2017:78). This explains why parents became sad at the fact they had adolescents with intellectual disability, which they had not expected.

b) Worry, fear of death and the future experienced by parents who have an adolescent with intellectual disability

It is not unusual for people to get worried when faced with a challenge that seems to have no solution. Parents were worried about what would happen to their adolescent if they passed away before the adolescent. They were worried and anxious about who

would take over in caring for the adolescent when they passed away since they lacked support while they were still alive. Parents were also worried about the future of their adolescents. One of the parents explained:

> *"lexi ni khongelaka xona vusiku ninhlekani, kunga se rhanga mina, niku axini tshiki ni lahla yena, niku Xikwembu xingani teki (tearful) loko ko ranga yena, hi ko xingata sala xi teka mina. axi rhangisi yena, ni lahla yena, hiko xingata sala xiteka mina , xinga niteki."* What I pray for day and night is that before I die, let God keep me away from death until I bury her, she should pass on first before me, so that I will be able to bury her, is then that God may let me die. (Participant 1, 57 yrs, grandmother)

One parent who was dependent on the adolescent's social grant indicated that she understood that the grant was helping them, but she had to take the adolescent to the hospital even though the grant would be cut off. She was worried about the safety of the adolescent when she was not around, as she had to work. She also showed concern about sexual harm and exploitation of her adolescent, and the possible consequences of a pregnancy. She said:

> "*Ende mali ee, yo yahi pfuna, mara vuhlayiseki bya yena kee, mali yita pfuna hina hi kotaku ku tifambela, hi kotaku ku ndla swin'wani na swin'wani, yena at the other hand yi, yi...mali ya yena yi nga n'wi tirheli. Loko se ni fambili, ni n'wi siyili, anga vulavuli. Hambi ko ndleka xin'wani ange byeli munhu. Ma swi vona danger ya vutomi bya yena yi le henhla ngopfu,"* That grant helped us, yes, but what about her safety. The money will help us who are mentally sound and able to do everything for ourselves, but what about her on the other hand, it, it...the money will not help her to be safe. When I go out, I leave her behind. She cannot speak, even if something bad happens to her, she will not be able to tell somebody. Can you see how her life is in danger, she is at high risk. (Participant 5, 34 yrs, sister)

She further elaborated:

> "*Kahle-kahle mina problem ya mina yile ka vuhlayiseki bya yena. Tiko ri bihili sweswi, wo hlamala n'wana va sale va rhipa."* My concern is on the safety of my younger sister. This world is cruel now. You will be surprised to find her raped. (Participant 5, 34 yrs, sister)

Having an adolescent with intellectual disability could bring fear to their parents in terms of the adolescent's future. The parents' fear was related to what would happen to their adolescents when they died.

Another parent feared that her adolescent would no longer be visited if she happened to pass on, because no one was visiting the adolescent now, except her. She said:

> *"Ene loko ari le axibedlhele akuna un'wani an'wi pfuxelaku handle ka mina, lero loko no kubudu ni lova, angahari na n'winyi, a kungaha vi na loyi anga ta n'wi pfuxela."* And when she is in the hospital, there is no other one who visits her except me, meaning that if I die, she will have no one, there will be no one to visit and look after her. (Participant 4, 55 yrs, mother)

Another participant said:

> *"I za i tela hi mihleketo yaku, we Xikwembu, na siku i vonaku ku mhi na famba, ku nga rhangi mina, aku rhangi lava, hiku ku hava munhu loyi anga ta ya aya n'wi pfuxela, ma swivona. Se swa...swa ni tikela."* Sometimes I have this thought, that, God, if you see that my days of living are coming to an end, let me not be the first to die, let my child die first, because there will be no one to look after her if you take me first. So it is difficult for me. (Participant 7, 46 yrs, mother)

According to Willingham-Storr (2014:7), some researchers identified that parents who have an adolescent with intellectual disability are worried about future provision for their children, and talked about the prospect of their death as a hidden concern. This

was mentioned briefly in relation to parental worries about what would happen to the adolescent when the parents were no longer around. This was also supported by Mbwilo, Smide and Aarts (2010:10) saying that parents expressed deep concern about the future when there would come a time when they would no longer be able to take responsibility for their adolescents with intellectual disability. Stress, as reported by parents, was associated with the worry and anxiety of caring for the adolescent with intellectual disability alone (Badu, 2016:24).

Although many parents were still relatively young people, the fear of what would happen to their children when they die seemed to pervade their lives, especially the parents of older children with more profound disabilities (Nda, 2012:5). Willingham-Storr (2014:9) highlights that parenting a child with intellectual disability is a role that leads to fear for the future. These fears can be further linked to stigma and isolation (McNally & Mannan, 2013:3).

c) Distress experienced by parents who have an adolescent with ntellectual disability

Challenges might make a person feel down, and that person might feel distressed by the continuous thoughts of those challenges. Parenting an adolescent with intellectual disability could be distressing. Parents explained how painful it was to have an adolescent with intellectual disability as the adolescent was partially or fully dependent on them to meet the activities of their daily living.

One parent said those who were taking care of the adolescent passed on. She wished someone else was alive to ease her burden, because as the adolescent's sister, she had to take over while she also had a family of her own. The following direct quotation supports this:

> *"...why va fambe hinkwavo. Ani swa endleka ku ku famba mutswari wun'we ku sala un'we...why ku fambe mhani, ku fambe papa... ku famba na kokwani. Maja-malume wa mhi anwi hlayisa...a lova."* Why are they all gone? It would have been better if it was one parent who passed away and one left...why my mother is gone and my father too,

> but why my grandmother also passed away? My uncle's wife took care of her...she also passed away. (Participant 5, 34 yrs, sister)

One participant said that when she visited the adolescent in the hospital, she came back in a different state of mind. Sometimes she got angry for no reason. She explained:

> *"Nkarhi wun'wani na loko ni ta ni fika ni n'wi languta, mo ni mi byela ku loko ni vuya la, ni vuya ni twa ku vava swinene. So i....swa ni tikela emotionally, a...ni hetelela ni nga vi a good person ene swa ni affecta na le, mo ni va honest. Nkarhi wun'wani I get angry, vo ni tiyisela vanhu. Kuri ku ano kwatela nchumu, kuri mhaka ya leyi ya swi sweswi ni nga hlangana na swona swa vana valava, hiku leswo tala leswi, ka mina ahi nchumu, ma swi vona."* Sometimes when I visit her in the hospital and look at her, let me tell you that when I come back home, I feel much pain. So it distresses me. I end up being not a good person and it affects me even at work, to be honest. Sometimes I get angry. People are just being patient with me. I become angry for no reason, but because of what I have encountered related to my children's situation. (Participant 7, 46 yrs, mother)

Parents also explained how painful it was to watch the adolescent in that condition of being aggressive and destructive. One said:

> *"Yhi, swa tika, ngopfu loko uri hava wo ku pfuna. A swi ni vavisa swinene ku vona leswi aswi endla, ni nga swi tivi ku ni fanele ni endla yini, ani ba na ku faya tinhundu ta vanhu. Swa vava swinene,"* Yes, it is difficult, more especially if you have no one to help you. It was very hurting for me to see what he was doing, not knowing what to do. He used to beat me, and damage other people's properties. It is very hurting. (Participant 8, 76 yrs, grandmother)

The literature review highlighted that parenting a child with intellectual disability is a role that can lead to family conflict, stress, feelings of exhaustion and resentment

(Willingham-Storr, 2014:9), which is distressing. Parents had no one and nowhere to take their burdens. They had to face them for the rest of their lives. Parents needed to manage the grief and loss at not having an ideal or 'perfect' child, but a child with intellectual disability. They also needed to deal with the problems associated with the behaviour, conduct and adaptive skills of children with intellectual disability. All this could be strenuous, burdensome and stressful for parents (Badu, 2016:20). Badu (2016:20) continues to say that it is distressing to take care of a sibling with intellectual disability, while having a family of one's own. According to Willingham-Storr (2014:2), a parent of an adolescent with intellectual disability is significantly more likely to experience parenting stress than parents of adolescent without disability.

d) Experienced feelings that parents were neglecting other family members

An adolescent with special needs, in this case, an adolescent with intellectual disability, drew most of the attention from the parent as he or she was partially or totally dependent on that parent to meet the activities of daily living. It left the parent spending more time attending to the concerned adolescent than with other family members. Parents tended to give more attention to the adolescent with intellectual disability and had less time for other family members. When the adolescent got admitted to the hospital, parents had time with other family members, though they had to take the adolescent home sometimes.

One parent wished the hospital would continue to care for the adolescent as she had to take care of her other child who had a physical health problem. She said:

> *"No kombela mi ni hlayisela, loko ni ri karhi ni ta, ni ta n'wi vona, eh, hi swona. Se loko ni va teka ni ta va hlengeleta, ani swi tivi, swi pfuka, loyi u la ku dyisiwa, ula ku suriwa, lavan'wani na vona ni va endlela."*
> I beg you to continue taking care of her. When I come to visit her, I will see her, eh, let it be. So when I take her home, I don't know, while I'm staying with my other sick daughter. What if my daughter relapses, how will I render care to the adolescent. She needs to be fed, bathed, and my sick daughter at the other hand need me. (Participant 1, 57 yrs, grandmother)

Another parent explained that she was unable to go and look for a job to care for her other children because she had to be there full-time to take care of the adolescent with intellectual disability. This is what she said:

> *"Se niku problem ya mina iku ani koti kuya ku tirheni, ni tirhela lavan'wani vana, lava nwani vana va hlupheka."* So, I told him that it is difficult for me to look for a job in order to keep life going, my other children are suffering. (Participant 3, 64 yrs, mother)

Another parent indicated that she had a challenge in staying with the adolescent (her sibling) as her other siblings were also staying with her since their mother passed on. Additionally, she had her own family as she was married:

> *"Se ni tshama na vona kwala. eh...thus why mi kuma ku ni na challenge ya yena, mi kuma ku ni nga n'wi teka-teki, ni na yona hiku lavaya vambirhi, va tshama kwala, na vona va lava mina. Na vana va mbirhi va mina"* I stay with them all…eh...thus why it is a challenge to take the adolescent to stay with me, I'm with my other two siblings. They also need me, and my two children too. (Participant 5, 34 yrs, sister)

Lafferly, et al. (2016:22) support this theme, saying that in some instance, it is a sibling who becomes the primary caregiver for his or her brother or sister with intellectual disability when a parent passes away. They further say that siblings may find themselves trying to balance the constant demand of caring for their brother or sister with intellectual disability, while simultaneously trying to raise a young family of their own.

Caring for an adolescent with intellectual disability require constant supervision, which could be time-consuming, and it demands a lot of patience from parents (Badu, 2016:21). An adolescent with intellectual disability could consume a disproportionate share of parents' resources of time, energy and money, so that other individuals and family members' needs go unmet. Social and family roles are disrupted because there is often not enough time, money, or energy to devote to everyone (Marriage and

Family Encyclopaedia Family Health, 2011:396). Adolescents with intellectual disability generally require more attention because they have additional needs to nondisabled persons (Resche, Mireles, Benz, Grenwelge, Perterson & Zhang, 2010: 139).

3.5.1.2 Theme 2: Experiences of support by parents who have an adolescent with intellectual disability

Most parents explained that they had no support from their family and community members. Few parents indicated that they had support from their family and the community.

a) Experienced a lack of support by parents who have an adolescent with intellectual disability

In order to deal with challenging situations, support was essential. Some people might be unable to deal with the situation without support. Most parents indicated that there was no support from their family and relatives, who tended to neglect parents who had an adolescent with intellectual disability. The fathers of adolescents with intellectual disabilitiy had abandoned them due to their condition. Parents, as well as their adolescents with intellectual disability, faced challenges of being neglected and rejected by family members, social isolation, and stigma.

a.i) Experienced neglect from family members and the community

Family members were expected to support each other in all situations as close contacts. In this case, it was different; family members tended to turn a blind eye on the parents who have an adolescent with intellectual disability and the adolescents themselves. Most of the parents indicated that they lacked support from their family members, which increased the stress they already had. The parents had to travel this stressful journey alone. Some stated that if they had support from family members, the situation might have been different. This was what some of the parents said:

“Ani se tshama ni vona va ta va khome 12,5. Ani se tshama ni vona sapoto ya vamakweru va mina, kumbe va ta, ene hi lava nga na swa vona.” I have never seen my siblings come with 12,5kg bag of mealie meal. I have never received support from my siblings, nor they visited me and they work well and they are successful. (Participant 1, 57 yrs, grandmother)

“Sweswi kwalaya axibedlhele hambi mo teka buku mi cheka, ina va mhanihulu, ina va malume, ku na va papahulu, kuna va hahani, i vanhu lava tirhaku kahle, na siku na rin'we, hambi mo cheka buku. Va vhe va ku kombeta ku ahi na mhaka na swona. Hambi mo cheka buku, loko unga pfuxelangi....futhi akuna munhu un'wani, i pfuxela hi mhi niri one.” Now at the hospital if you can check the book, she has aunts, she has maternal and paternal uncles. If you can check the book, if it is not me who visits her, there is no one else. (Participant 5, 34 yrs, sister)

“A swi...kahle-kahle no hlupha hi support system, not ya normal...ya...veri i yini...ya moral support, ee ma swivona. Vanhu va swi vona swi tetani. Na la kaya a ka ha ngheni munhu. A va tshuneli hambi maxaka. Ani vanghana loko va nga swilavi u nge va fosteli. ...ku va ni bebule n’wana loya, na hari hava xaka sweswi.” Thus why na le xibedlhele loko mo swi languta ami se tshama mi vona munhu u n'wani handle ka mina.” Truly, my problem is lack of support, I mean, moral support. When people see it like that, they no longer visit me. They no longer come close to me, even my own relatives. If friends are reluctant to visit me, I can’t force them. But my relatives...by having this adolescent with disability, I no longer have relatives now. This is why even in the hospital, if you have observed well, you have never seen anyone else other than me. (Participant 7, 46yrs, mother)

She continued to indicate that if she had a support system, her situation would not have been the same. It was difficult for her without a support system.

> *"Ni landza hi vanhu va four andzhaka mina. Mara na un'we wo khera kumbe wo tsunduka ku kuna xihlangi lexiya kwahala...se i tichallenges leti ni hlanganaku na tona. Leti ani twisisi ku loko ku ri ku akuri na la ni sapotaku hi...like sweswi ni swivulaku...swin'wani ani ta...na mbilu ya mina ayi nga ta vava ku fika la yi nga ku vaveni. No ti khoma kahle-kahle mbilu ya mina ayi tshamisekangi, ma swivona (emotional). A swi olovi swa ni tikela swinene ma swivona."* I'm a firstborn at home, I have four siblings that were born after me, but not even a single one that cares or remembers that I have a child with intellectual disability. So, those are the challenges that I meet. I understand that if there was somebody who gives me support in this situation, even my pain would not be like this. I just control myself, but my heart is not settled, you see. It is not easy, it is difficult for me. (Participant 7, 46 yrs, mother)

Willingham-Storr (2014:2) indicates that levels of stress are affected by levels of formal support from professionals and social support from partners, family members and friends. Some communities perceive intellectual disability as a punishment for what one has done wrong. This would perhaps explain the minimal support received from the community (Taderera & Hall, 2017:283). Extended family members might be unwilling to contribute to and support parents in raising an adolescent with intellectual disability for fear of associated discrimination and stigmatisation (Resche, et al. 2010:139).

a.ii) Experienced rejection from their husbands

Normally, husbands and wives stand together for better and for worse. They are expected to share and hold each other's hand in times of trouble and challenges, but it seemed as if the husbands of the mothers of adolescents with intellectual disability, or the fathers of those adolescents, could not stand to have such an adolescent. A majority of the mothers were rejected by the adolescents' fathers due to the adolescents' intellectual disability. The mothers had to carry the burden of raising and caring for the adolescent alone. Participants shared:

"Papa yena va kona. Va va hlongoli aha ri ntsongo, vaku muka kaya na n'wana wa wena wa xigono. Na ku nwi tiva mbava wa yena sweswi, ani tshembi. Va va hlongoli aho tshama sweswiya, va swivona ku n'wana loyi ingaku anga kahle." His father is alive. His father kicked them away when he was a toddler, saying to his mother that she must leave the house because she had given birth to a child with a disability. He no longer knows his father. His father kicked them out of the house when the child learns to sit, when his father realises that the child seemed to have a disability. (Participant 2, 51 yrs, aunt)

"Papa wa yena ku sukela laha va nga swi vona ku u taniya, a va zangi va yi nghena..." Her father has never mind about her since he realised that she has an intellectual disability. (Participant 3, 64 yrs, mother)

"Mara nuna ari kona, ari joni anga posi. Loko a fanele avuya yiva nyimpi hiku mhi ni bebule....ni famba hiku mhi nina n'wana wa xigono. Em, sweswo taniya. Se aku famba hiku una n'wana wa xigono, uta kuma van'wani va ta ku teka." I had my husband. He was in Jo'burg and not maintaining his family. He hated to come back home because I gave birth to the child with intellectual disability...he said that I must leave his house because I have a child with intellectual disabilities, just like that. So he said I must go with my child, I will get somebody who will marry me. (Participant 4, 55 yrs, mother)

McNally and Mannan (2013:2) support the view that rejection by fathers is common; spousal and immediate family support is therefore absent, and the onus of care falls on the mother. Mudhovozi, Maphula and Mashamba (2012:148) also emphasise that in Limpopo, South Africa, the burden of raising a child with intellectual disability lies with the mother. Similarly, Harper, Dyches, Harper, Roper and South (2013:14) indicate that women are often abandoned by their husbands and have to bear the brunt of caring for the child with intellectual disability alone.

a.iii) Experienced social isolation

There are some challenges that, if a person did not get the required support, could lead to social isolation. In this case, due to the lack of support, some parents experienced social isolation. When parents took their adolescent home, they had to stay with the adolescent full-time as he or she needed extra care. Some said that if the adolescent was at home, they spent all their time at home, looking after and caring for the adolescent, as they could not afford to hire a nanny. It meant that the parents no longer socialised or interacted in community activities as caring for an adolescent with intellectual disability was all-day work. Some explained that they lost interest in social interaction due to anxiety at what the people would say about their situation of having an adolescent with intellectual disability. Participants shared:

> *"Sesi aku nga ri munhu wo ya helo, hiku ku sukela loko vari na n'wana luya, avo tihlayisela n'wana wa vona, va tivonela TV kwala kaya va tshamili."* My sister was a person who usually stays at home since she had that child, she will stay at home and take care of her child, or watch TV. (Participant 2, 51 yrs, aunt)

> *"Ene ani swirhandzi ku ni tikuma ni ri na vanhu vo tala, ano va nyenya. I, i...vanhu va vavisa, vanhu va plana ku vavisa munhu, ma swivona. Se ni avoida...ani lavi ku ya la ku nga na vanhu vo tala, la ni nga tata vuya ni vavisekili. Loko ko va na tifunction na atenda hiku ni munhu, no tirhisa vutlhari ku atende ka swona...like ni avoida leswi...ku loko no tikuma niri na loyi hi nga hetelela hi vavisana. Nkarhi wo tala ni tala ku va loko ku yiwa ka function, ni va na vanhu lava va nga vs tiviki at all, kumbe va nga ni tiveliki. Ee ni hanyisa sweswiya, na le ntirhweni, sweswi ka hlanganiwa hinkweni aniyi."* And I don't like to find myself where there are many people, not that I hate them, no, people can hurt you, people can plan to hurt you, you see. So I avoid being where there are many people, where I will come back being hurt. Most of the times when there are functions, I prefer to be with the people who do not know me at all. Yes, that's how I live. Even if there is a meeting at work, I don't go. (Participant 7, 46 yrs, mother)

> *"Ani kumeka ni nga swikoti na kuya helo, hambi a kerekeni ani nga yi, hiku ata fika le a sungula ku vanga nyimpi, ku ni ta vuya kaya kumbe afaya timovha ta vanhu."* I was unable to go anywhere else, even at the church, because he would cause trouble there and threw stones at the cars that were there. (Participant 8, 76 yrs, grandmother)

Thwala, Ntinda and Hlanze (2015:213) state that parents who have an adolescent with intellectual disability encounter challenges that include social isolation. McNally and Mannan (2013:2) are in support when they refer to increased isolation experienced by parents as caring for children with intellectual disability is not regarded as the community's responsibility.

a.iv) Experienced stigma

Some community members seemed to disapprove of intellectual disability, mostly the severe and profound forms of disability. This was why parents with an adolescent with intellectual disability were stigmatised. Most of the parents reported a lack of family and community support. The family and community members distanced themselves from the parents who have an adolescent with intellectual disability. One of the parents said that her neighbours thought the condition was contagious as her adolescent also had epilepsy. Another participant explained that family members seemed to be uncomfortable living with the adolescent with intellectual disability, perhaps because they did not know how to treat her within the family. Here was what she said:

> *"Ni ze ni n'wi teka nkarhi wun'wana hi Good Friday, ni va niri na yena kwala. Ni swi vona ku...wa swi vona ku i endla vanhu va fila uncomfortable. Loko va...ani ava switwisisi naku vata hanya na yena njhani. O kota himina ni nga makwenu wa yena. Ee, ava switwisisi ku va fanele van'wi treata njhani, va hanya na yena njhani, ava switwisisi."* It was Good Friday when I took her to visit me here. I realised that it made people feel uncomfortable. When they...they don't understand how they should live with her. It's me only who is able to live with her because she is my sibling. Yes, they don't

understand how they should treat her, how they should live with her. They don't understand. (Participant 5, 34 yrs, sister).

Some parents complained about the attitude of their neighbours toward them and their adolescents with intellectual disability, which made it difficult for them to interact with their neighbours and also to participate in community activities. The community members seemed not to understand what intellectual disability was. This appeared to be the reason why it was difficult for them to support parents who have an adolescent with intellectual disability. One of the parents explained that her neighbour came and complained about her child who had seizures, thinking that the adolescent had transmitted epilepsy to her child, as the participant had two children with epilepsy, including the adolescent with intellectual disability. She said:

> *"Unw'ana ka va lava ni tshamaku na vona, hikuva kuri na swin'wani ingaku va vulavurili, va byelana. Se ata a fika la ka mina, se uri, swi leswi swa mavabyi lama nga la, inge swi tivi ku swita na vana va ka mani,...hikuva nwana wa yena a fitili...thus why na gede mi kuma yi khiyiwili. Vana va mina ava humi va nga ta chela vana va vona mavabyi."* One of my neighbours had come to me. It seemed as they have first conspired about me before with others. So she told me that there are children who are spreading this disease, because her child had fits the past few days. That is the reason you found my gate locked. I don't want my children to go outside to spread epilepsy and intellectual disability as my neighbours thought. (Participant 7, 46 yrs, mother)

She further explained:

> *"Mara mintirho ya vona ya komba ku avava lavi vava lava. Van'wana va swi vula like...hiku vulavula, vaku swa tlulela, ma swi vona, se ni hetelela ni ku thus why va ngati, na vana va vona, va chava ku tluleriwa hi switshetshela, ma swi vona"* But their actions showed that they don't like my children. Some said just in passing that this condition can be contagious. So I realised that this is the reason why

> they distance themselves from me and my children. They feared that epilepsy and intellectual disability could be transmitted to them. (Participant 7, 46 yrs, mother)

The lack of support from family and community members seemed to predispose participants to stigma and discrimination (Taderera & Hall, 2017:3). Gupta, Mehrotra and Mehrotra (2012:41) indicate that the stigma associated with intellectual disability is so pervasive that support from the family and society is limited. In his research, Badu (2016:21) explained that another source of stress was managing negative attitudes of the community. Friends, neighbours and people in the community may react negatively to the intellectual disability through avoidance, disparaging remarks or looks, or overt efforts to exclude parents who have an adolescent with intellectual disability. An explanation could be that disadvantaged communities may lack adequate resources for health care, experience poor access to vital information on the well-being of families, and have low education levels (Resche, et al. 2010:139).

b) Experienced an abundance of support by parents who have an adolescent with intellectual disability

Parents who were facing challenges at having an adolescent with intellectual disability needed constant support from different structures for them to be able to manage and cope with those challenges. Although most of the parents reported a lack of support, there were a few participants who indicated that they got support from their family members, their employer, community and government services.

b.i) Experienced support from family members

Family members are the basic support system for parents who have an adolescent with intellectual disability. A few parents indicated that they got support from family members, which was helpful to their situation. Support from family members could help the parents cope with the burden of caring for the adolescent with intellectual disability. Some parents said:

> *"Ene lo ani pfuna ngopfu loko niri ku tirheni i mhani. Ava ya vaya n'wi pfuxela."* The only person who helped me to check on my child was my mother and she is no more. (Participant 3, 64 yrs, mother)

She continued to say:

> *"...anwi rhwala hi movha ata na yena, hi pfula gede liya, va hi tlakurisa hi n'wi veka lahaya mubedweni."* When I take her home, I have to hire a car that will take her home. They have to help me to carry her and put her on the bed. (Participant 3, 64 yrs, mother)

Another participant shared:

> *"Ani n'witeka ni n'wi vuyisela le ka mhani la ni nga tswariwa kona, then niya niya tshama kwale, ni sukela kwale ni kha ni ya ntirhweni. Nkarhi wunwani va ni olovisela vaku hayi, ni ta tshama na yena. Se sweswi se va kurili,"* I used to take her to my mother's place at the village, then go there to stay with her, so that my mother can take care of her when I went to work. Sometimes my mother stayed with her until I get off days, then take over, but now my mother is too old to look after my child. (Participant 6, 48 yrs, mother)

Ha, Grenberg and Seltzer (2011:405) highlight that family support systems are frequently relied on as coping strategies. This support is necessary since the parents are faced with additional responsibilities and they experience many problems relating to care (Mbwilo, et al. 2010:9). Aldersey (2012:5) states that family support encompasses the individualised determination of each family's needs, strengths and preferences as the basis for accessing resources (that is, emotional, informational, financial and instrumental) to enhance parents' quality of life.

b.ii) Experienced support from employers

Employers could be very understanding of the situation of the parents who have an adolescent with intellectual disability. A few offered them necessary support as some parents were physically frail. A parent explained:

> *"...mhani lavayani ni tirhaku ka vona, nilo nikiwa hi Xikwembu, Nina ten years, nilo nyikiwa hi Xikwembu. Ee, avani tirhisi swilo swo karhata, na waxeni ava ha pfumeli kuri ni hlantswa...Loko loyi swi tika na vusiku swiku bvindlu-bvindlu na vusiku ni va foyinela, nto vona ximovhani hi xexi, hambi sweswi minga tshama kwala loko no teka foni niva fonela mingo va vona sweswi, ingaku i n'wana mhana mina, i tlula na n'wana mhana mina, uto vona hi valava."* That mother who I work for, I was given by God. I have been working there for the last ten years, I was given by God. She only allows me to work those light jobs. She doesn't allow me to do her washing...when my child relapses at night, I use to phone her, and she will come as soon as possible, even if I can call her now, you will see her car coming here. She is like my biological sister, she is more than a sibling. (Participant 1, female, 57 yrs, grandmother)

Heywood (2010:22) states that some parents are unable to take up employment due to their caring duties. This might result in the family becoming poor. Parents who have an adolescent with intellectual disability thus need support from their employers. Heywood (2010:22) also indicates that parents of adolescents with intellectual disability were employed significantly less frequently in comparison with those without an adolescent with intellectual disability.

b.iii) Experienced support from community members

Community members' support for parents who have an adolescent with intellectual disability was important as the parents experienced that sense of belonging which helped them to cope with their situation. A parent stated:

> *"Va makhelwani lava...ngopfu-ngopfu lava hi nga langutana na vona, hawa hi khomani kahle. Loko ari kwala va ta va ta n'wi pfuxela."* My neighbours...most especially those opposite my house, we are well related. When my adolescent is here, they use to come and check on her. (Participant 6, 48 yrs, mother)

Some parents of children with intellectual disability generally rely on social support to cope with their situation (Ha, et al. 2011:405). An adolescent with any form of disability is a heavy burden on the parent; there is thus a great need for support from the community (Mbwilo, et al. 2010:9). However, Taderera and Hall (2017:283) comment that community members often distance themselves from parents and adolescents with intellectual disability.

b.iv) Experienced support from government services

Government should play a significant role in providing support to those parents who have an adolescent with intellectual disability in terms of the provision of accessories and physical resources to make caring for the adolescent bearable. Though limited, government played an important part in accommodating those adolescents with intellectual disability in the psychiatric hospital. There was a shortage of day-care centres for adolescents with intellectual disability in Giyani area. The psychiatric hospital in that area no longer admits adolescents with intellectual disability who are not receiving treatment. Those who were already there were fortunate for now. However, parents were grateful to the government for admitting their adolescent with intellectual disability. One parent said:

> *"Ene mfumu lowu wu ni pfunili, ani hlupheka, ma ku tiva ku hlupheka, ha, wu ni pfuni ngopfu, wu ni pfunili."* And this government has helped me so much by admitting my child in the hospital. (Participant 4, 55 yrs, mother)

Some participants received RDP houses and they now had a place to call 'home', because of the government's support.

> *"One room liya ku ake yena (patient's mother), a khoma-khomanyana. Leswi ni swi vulaku, loko aku ngova RDP ya leyi, ami tava mi ya hlaya swo kasi nwana wa kona na loko va nwi teka u ta ya tshama kwihi. Sweswi swa antswa hi ku ni na RDP."* That one room that you see it has been built by her (the adolescent's mother) she was holding some piece-jobs. That is why I say if it was not for this

> RDP, you would have wondered that even when I take her, where would she stay. It is better now that I have an RDP house. (Participant 1, 57 yrs, grandmother)

She continued to say:

> *"...ni tlhela ni khensa na mfumo, na social worker loko ani byela timhaka ta ku mapasi, nilo fika ni tshama hansi na yena niku na mi khensa."* I want to thank the government and the social worker for their continued support, assisting with the application of identity document for my adolescent, I'm thankful. (Participant 1, 57 yrs, grandmother)

Another research study (Taderera & Hall, 2017:283) indicated that through a combination of social and economic goals, the well-being of parents who have an adolescent with intellectual disability lies at the heart of social development. In Giyani, for an adolescent with intellectual disability to be admitted in the psychiatric institutions, the social development department has to motivate through the social worker's assessment and recommendations. That was why adolescents with intellectual disability were placed in psychiatric hospitals.

Generally, parents of adolescents with intellectual disability reported feeling less burdened when their adolescent moved to an out-of-home placement. Parents also had time to interact and participate in community activities, though they feared the stigma attached to having an adolescent with intellectual disability. Government also plays a role in the administration of social grants that adolescents with intellectual disability are entitled to (Taderera & Hall, 2017:283).

3.5.1.3 Theme 3: Caring challenges experienced by parents who have an adolescent with intellectual disability

To have an adolescent with intellectual disability comes with significant challenges. Parents who have an adolescent with intellectual disability explained the difficulties they encountered when caring for these adolescents. Some explained how difficult it

was to manage and control the adolescent because of their behaviours and their deformed physical development. Parents who have an adolescent with intellectual disability became more stressed when they failed to manage the behaviour of their adolescent with intellectual disability as some adolescents were aggressive, destructive and violent. These behaviours might lead to family instability and poor relationships with neighbours and relatives. Some had to pay for the damages done by the adolescent with intellectual disability by using money from loan sharks. Parents might also experience stress caused by the extra effort required to manage the behaviour. Caring challenges included the physical frailty of the parent, difficulties in managing the adolescent, lack of physical support, and poverty.

a) Experienced physical frailty

It might be difficult for parents to care for their adolescent with intellectual disability while having physical health problems themselves. A majority of the parents complained about physical health and psychological problems. One participant explained that her situation interfered with her job. Some parents indicated that they were no longer able to care for their adolescents because of their physical health challenges. Participants explained:

> *"Himpela aningata swi kota, aninga ta swikota. A ninga ta swikota, ninge he nwitlakuli mina, ninga wa nayena, nenge lowu wani brija nwana mhan,"* Surely I cannot do it, I can't do it. I can not be able to take care of her, I can't be able to carry her anymore, I can fall down with her, my legs make it difficult for me, they are painful. (Participant 1, 57 yrs, grandmother)

> *"Loko i fanele u n'wi vekela pampers wo lwa anga pfumeli. I...anga pfumeli nchumu, no dodombana na yena. Leswi se mhi ni nga khegula se ni tivabyelaku na mina hi...ehe, ani switivi. Loko niku na vabya no pfa niti ni titwela sululwani, ahi mbilu, i mbilu, i mbilu."* When you change her napkin you have to struggle, she refuses, she ...she is difficult altogether, I have to struggle with her. And now I'm becoming old and sick...yes, I don't know. When I say I'm sick, I mean

sometimes I feel dizzy, is it not because of my heart, it is, it is. (Participant 4, 55 yrs, mother).

"Ni ze nkarhi wunwani va za va ni chronika axibedlele vaku BP yi le henhla. Ni ze ni fambela Xibedlhele, ku ngava kumbe lembe...I'm sure i last...last of last year, ee, swinghenelela na leri nga helanyana. Yi ve yi yava kahle kwala xikarhinyana." At one stage I went to the hospital, they said I have elevated blood pressure. I went to the hospital several times because of my blood pressure, it may be a year or so...I'm sure it was a year before last, yes, until the middle of last year. It started to be controlled for sometimes this year. (Participant 6, 48 yrs, mother)

Somatic and psychological health, emotional health, quality of life and well-being have all been demonstrated to deteriorate among parents of adolescents with intellectual disability (Wittenberg & Prosse, 2013:489). Because of increased parental responsibilities, parents of adolescents with intellectual disability can be at high risk of experiencing depression, physical health problems and decreased quality of life (Resch, et al. 2010:139).

b) Experienced difficulties in managing the adolescent

Intellectual disability can be mild, moderate, severe or profound and some individuals can also be aggressive, destructive or violent. The adolescent might be unmanageable depending on the severity of his or her intellectual disability. Parents had difficulty in caring for their adolescent with intellectual disability, as some needed physical power. Some parents explained how difficult it was to care for an adolescent with intellectual disability at home, as they had to bath them, feed them, change diapers and supervise them. Performing these activities were stressful as some adolescents were difficult to manage and needed constant attention. Some parents explained the difficulties in caring for an adolescent with intellectual disability that they experienced as follows:

“Ahi xanisa loko hi la ku nwi hlambisa hi nga swikoti ahi ba a tilumetela, u kuma ku loko u n'wi nika swakudya a tifayetela hansi hi nhloko. Se hi yima hi nga ha swi twisisi, hi nga swikoti ku n'wi khoma hi nwi lan'wisa sweswiya hi nwi tshika. Hambi loko tati va hari kona na vona ava ba.” He was difficult, when we bathe him it was not easy, he will beat us, and bite himself. You find that when you give him food, he will hit his head against the floor. So we just looked at him not knowing what to do, not able to manage him and end up leaving with him like that. Even when his mother was still alive he would beat her. (Participant 2, 51 yrs, aunt)

“Problem ya kona iku anga koti ku tiendlela nchumu, mara ku tidyisa wa tidyisa, swi helela kwalanu. U la ku hlambisiwa, i la ku nciciwa napkin, ene ani swikoti ku n'wi tlakula niri nexe, ni n'wi yisa bavhini, yena xa yena iku titshamela ntsena. ani na ku vulavula anaga swikoti.” The problem is that she cannot do anything for herself, but she can only feed herself. She needs to be bathed, to be changed soiled napkin, and I can’t pick her up to the bath alone, what she can do is to sit only. She can’t speak. (Participant 6, 48 yrs, mother).

“Ani nkarhi lowa a kumeka ari la kaya, anga fayeteli nhundzu ya vanhu ntsena, na mina ani ba. Kumbe hi swona swi nga endla ku mhani wa yena anga n'wi lavi. Hiku aku ba nkarhi ahi ba la kaya...” When he was staying here at home, he did not only damage other people’s properties, he also beat me. Maybe that was the reason why his mother neglected him. There was sometimes where he used to beat us all at home... (Participant 8, 76 yrs, grandmother)

She continued to say:

“Se ni nge he swikoti ku tshama na yena full-time, hiku ani anga swikoti ku tiendlela nchumu, loko ari kona ni fanele ni n'wi hlambisa, ari nkulu ari taniya, ni fanele ni nwi hlantswela, ni fanele ni vona ku u tshama akha aya toilet hiku anga vuli loko alava kuya toilet, u lava ku

byeriwa. Se mina ana hari na matimba yo nwi hlambisa, no ti vabyela se na tivabyela." So I will no longer be able to take care of him full-time because he cannot do anything for himself. When he is here, he needs to be bathed, being grownup as he is, he needs to be reminded to go to the toilet, or he will mess himself up. So I no longer have the power to bath him, and I am sick. (Participant 8, 76 yrs, grandmother)

Parents had to deal with numerous physical, behavioural and developmental issues associated with adolescents with intellectual disability, such as providing personal skills, for example, toileting, eating, bathing and helping females during menstruation (Badu, 2016:24). Parents of adolescents with intellectual disability suffered from exhaustion and stress due to the intensity of care required. Feeding, clothing, bathing and diapering an infant is much easier than doing the same task for someone who weighs more than 80 pounds (Thwala, et al. 2015:207). Parents needed to deal with problems associated with the behaviour, and adapt skills for adolescents with intellectual disability; all this could be strenuous, burdensome and stressful for parents (Badu, 2016:20).

c) Experienced a lack of physical resources

Participants faced the challenge of a lack of physical resources to support their adolescent with intellectual disability, as well as professional support. Some of the adolescents needed accessories like wheelchairs that parents could not afford so they ended up carrying the adolescent on their backs or in their arms, which could be heavy for them and strained their body. Participants shared:

"...ninga ta swikota, ninge he nwi tlakuli mina ninga wa nayena" I cannot be able to take care of her, I can't be able to carry her anymore, I can fall down with her... (Participant 1, 51 yrs, grandmother)

"Anga zangi a ringeta na ku famba. Loko va n'wi yisa axibedlhele avo n'u bebuka, kumbe va n'wi tlakula vava na munhu va khomisana." When she takes him to the hospital, she will carry him at her back, or

carry him by her hands with the help of somebody. (Participant 2, 51 yrs, aunt)

"Se hi yona problem leyi loko no tshama na yena yi nga ni karhata hiku aniri ani...ni nge swikoti kuri ni n'wi teka niya n'wi veka hala, i nkulukumba." So that is the problem that I'm having. If I can stay with her it will be difficult for me to carry her around, she is now a grownup person. (Participant 3, 64 yrs, mother)

Previous studies in this area have shown that services do not always address the needs of parents and do not offer continual support (Willingham-Storr, 2014:4). Challenges in parenting adolescents with intellectual disability are also encountered because of a lack of resources related to daily living support (Resch, et al. 2010:139).

d) Experienced poverty

In most cases, adolescents with intellectual disability were from families of low-income status. To care for an adolescent with intellectual disability could come at great expense and be demanding on parents as they need extra cash for the adolescent's well-being and activities of daily living. Parents who have an adolescent with intellectual disability mostly depend on social grants. Some parents worked as domestic workers, and some parents were casual employees. Most parents had financial difficulties and inadequate housing.

d.i) Experienced financial difficulties

Financial strain added to the stress that the parents already had since the special needs of the adolescent with intellectual disability could require more finances from parents. Some participants stated the following about how they make a living:

"Ene na vusiwana abyiri kona hiku, aniri na byo vukati bya kona abyi nga nyawuli." So there is poverty within the family. I was married but my marriage was useless... (Participant 3, 64 yrs, mother)

"Axibedlhele avaku loko o kota ku tshama kona hiku ani va ni hlamuserili na timhaka ta grant ya yena. Hiku yona hi yona ayi ndla ku vana lavaya vava stable va tshama ndhawu yinwe ni kota ku loko a horili hi yho ayi xava swakudya na swin'wana na swin'wani, mara niku ani na choice." That's why I applied at that hospital for her, and they explained to me that they are going to cut off her grant. Though it was helping for my sibling to be stable and stay together, because I was using that grant to buy them food and other things, but I told them I've got no choice. (Participant 5, 34 yrs, sister)

"Hi mina ani hakela milandzu ya kona, kuve na mali ani ri hava, ano ti kayakayela. Miri mali ya mudende yi na ka yini. Loko a fayetela swilu swa vanhu, ani ya ka machonisa nita kota kuhakela swilo swa vanhu." I used to pay for damages he made. Though I did not have enough money, I was just struggling. Old age grant is too little to pay for those damages. When he damages other people's properties, I used to borrow money from the loan sharks to pay those damages. (Participant 8, 76 yrs, grandmother)

Thwala, et al. (2015:208) agree that raising a child with intellectual disability might be more expensive than raising a typical child. These expenses may arise from medical equipment and supplies such as wheelchairs, medical care, caregiving expenses, and specialised transportation which the parents could not afford. Resch, et al. (2010:139) indicate that, exacerbating these financial challenges is the finding that children with intellectual disability are significantly more likely to live in families considered to be poor. They continued to say an adolescent with intellectual disability might also increase the likelihood of the family being poor. Families of children with intellectual disability, regardless of the type of disability, experience higher expenditure than other families (Resch, et al. 2010:139). Money was a significant problem for some parents, particularly where they depended on the disability allowance for the care of their child, such as social grants (Nda, 2012:5).

d.ii) Experienced inadequate housing

A proper living environment forms the basic need of every person. Everyone has the right to suitable housing. Housing was another problem for parents who have an adolescent with intellectual disability. An adolescent with intellectual disability needs an environment that could best suit him or her, like having a room with adequate accessories such as suitable bathtubs, a bed with side rails, feeding cups, wheelchairs and other equipment that are of help. Some parents had received RDP houses, which was good, but they had no suitable accessories to cater for the adolescent with intellectual disability.

> *"Kwala ku nga na semende aku akiwe xi-two-rhunwana, loko u ku e (leaning on it), xiku dididi (shaking). Loko ri duma lava ava baleka lava na sesi wa yena vani siya kwalaya vaya ka un'wani."* That side where there is that cement slab, there was a cracked two-roomed house where we use to sleep in. When thunderstorms strikes, my children used to go to our family friend for shelter. (Participant 1, 57 yrs, grandmother)

> *"Ni tshama ka xi three rhun'wana, axilo handzuka, a xilo hlakala na munhu xi three-rhun'wana xexo, yi pandzekili andzeni, yi pandzekerili, hiku ani endla hi switina swo hisa."* I stay in a three-roomed house which has cracks all over, it is cracked because it had been built with mud bricks. (Participant 4, 55 yrs, mother)

> *"Ene la phela problem yin'wani akova ka mina, ene ahi le muntini wa mina na nuna wa mina. La hi le ka va mhana nuna wa mina, ma swivona. Na kona kwala family yi kulukumba, loko ku fika minkarhi ya leya tifestive seasons, vava va vuyeterili joni. Ku va ku tele vhele, hiku na vana va mhani-hulu va tshama kwala, ene va hlayili."* The problem is that where we are staying is not my home, it is not my and my husband's house. This is my mother-in-law's house. Even here it is a large family. When the festive season comes, you found them all here, even those who are in Jo'burg. The house becomes full, because

even the children of my husband's aunt stay here and they are many. (Participant 5, 34 yrs, sister)

Some research indicates that the economic difficulties experienced by parents affected the provision of care for the adolescent; challenges were experienced in sustaining basic needs, education, as well as housing (Mbwilo, et al. 2010:10). Willingham-Storr (2014:10) highlights that families of adolescents with intellectual disability were disadvantaged financially, in terms of housing and employment, as well as it having detrimental effects on their marital relationship.

3.5.1.4 Theme 4: Positive coping mechanisms experienced by parents who have an adolescent with intellectual disability

In difficult situations, a person has to find ways to cope and there are stages of grief before acceptance. Parents showed coping in their situation by putting their trust in God and gradually accepting their adolescents' condition.

a) Experienced positive coping through their faith in God

To have faith in God was cheap and every parent could afford it. It just needed dedication and trust. Parents who had an adolescent with intellectual disability seemed to try to find ways to deal with the stress themselves. In all the interviews, parents indicated that it was only God who kept them going. This is how parents indicated their trust in God:

> *"Se ani mina ni nge dlayi, ni nike hi Xikwembu, ani switivi ku loko Xikwembu xi ni nikise leswiya xi hlekete yini. No fanela ni swi amukela iswa mina."* So I will never kill my child, it is a gift from God, I don't know His intentions of giving me this child. I have to accept it. She is my child. (Participant 4, 55 yrs, mother)

> *"Hi leswi Xikwembu xi nga ni nikisa swona. Mhi no pfumela ku hi leswi Xikwembu xi swi lavisaku swona ka vutomi bya mina."* This is what

God has given me. I believe that this is what God wants my life to be. (Participant 5, 34 yrs, sister)

"So a...no ti byela ku, God is in control, hi leswi ni nga dyondzisiwa swona mina. Kahle-kahle mhi ni ri xiyimo lexiya, no hetelela niku ni yo pfuniwa hi Xikwembu ke, ku za ni fika la ni nga la." So I tell myself that God is in control. That is what I was taught. I end up telling myself that it is God who helped me up to this far. (Participant 7, 76 yrs, grandmother)

Ha, et al. (2011:406) state that among people of African descent, including parents of children with intellectual disability, spirituality and family support systems are frequently relied on as coping strategies in times of adversity. Parents' spirituality, which often included a belief in God or attending church, serves as an important coping strategy to assuage their distress (Ellen & Mashall, 2010:232). Current literature by Dura-Vila, Dein and Hodes (2010:171) asserts that some mothers of children with intellectual disability generally rely on coping resources including social support, hope and spirituality that affect mothers' experiences positively. Parents emphasised their belief in God and His power to carry them through their experiences of caring for an adolescent with disability (McNally & Mannan, 2013:4).

b) Experienced positive coping through acceptance

After the difficult situation that the parents experienced, they eventually found strategies to finally accept their situation, especially if the situation was beyond their control, or if they could not change the situation. Parents who have an adolescent with intellectual disability tended to accept the adolescent's condition as they had to live with it for the rest of their lives. Though it was not easy, with time they tended to become used to this situation. Parents showed acceptance when they said:

"Se sweswiwani mhe ni ve ni hlamusela niku phela vutomi byi nge yimi, hiku vatswari va lovili ni sale na vamakwenu, na swona un'wani u disabled, vutomi swiboha byi ya mahlweni." I have explained that this does not mean life has to ends here. Just because our parents

are no more and left me with my siblings and the other one had intellectual disability. Life has to go on. (Participant 5, 34 yrs, sister)

"Loyi ani nyumi ku famba na yena. Futhi ni ngezi ni mi hembela. Na suka na yena kwala vhakacha na yena, mhi ani na problem, ene hi famba hi public transport. Hiku mina ani ni swi amukerili ku nina makwenu wa disable, ene sweswi hi mhi mhana yena." I am not ashamed to walk with her. I will not lie about that. I can travel with her using public transport. I have accepted that I have a sibling with intellectual disabilities and now I'm her mother. (Participant 5, 34 yrs, sister)

"Xiyimo lexi anga eka xona ni xi amukerili manjheni, axo ni hlupha ...axi ni vavela aku sunguleni. Emm, aku sunguleni a xini hlupha swinene, ni vuye ni gina ni xi amukela. Se ni xi amukerili." I have now accepted my adolescent's situation. It was difficult for me...it was painful in the beginning. It was very difficult in the beginning, but I finally accepted the situation. (Participant 6, 48 yrs, mother)

Heather and Aldersey (2012:37) report that many parents take comfort in their spirituality, which helps them view their child as a blessing or a test of their faith, rather than a burden. In spite of the increased level of stress experienced by parents of adolescents with intellectual disability, many parents of such adolescents are well-adapted and appear resilient in the face of challenges (Heather & Aldersey, 2012:3).

3.6 FIELD NOTES

Field notes were written during and after the interviews. These field notes include observational notes, theoretical notes, methodological notes and personal notes. These notes are discussed next.

3.6.1 Observational notes

The interviews were conducted with parents who have an adolescent with intellectual disability at their homes. The parents were anxious at first, but during the interviews they became relaxed and told their stories. It seemed as if they were waiting for this time so that they could ventilate what was within them. They looked sad, and some were also tearful.

3.6.2 Theoretical notes

Parents who have an adolescent with intellectual disability had to care for the adolescents in an unsuitable environment when they took them home. Some had to sleep on the floor to protect them from falling as they did not have cot beds. It was difficult to render care to those adolescents while sleeping on the floor. The parents appeared to be stressed.

3.6.3 Methodological notes

After the interviews, the field notes were transcribed. The main question was asked, and the participants had time to openly respond to the question. The researcher had to direct the participants to the question when necessary, and asked follow-up questions when needed.

3.6.4 Personal notes

The participants shared their experiences through the interviews. The researcher could see that the participants were stressed at having an adolescent with intellectual disability. Their experiences were sensitive, mostly because the parents were not getting the necessary support. Some explained how difficult it was to care for the adolescent alone. The researcher felt guilty as there was nothing she could do at that time.

3.7 SUMMARY

Research findings showed that parents who have an adolescent with intellectual disability experience stress. The source of stress was related to emotional responses. Most of the parents experienced a lack of support, caring challenges, yet positive coping mechanisms. This meant that to have and care for an adolescent with intellectual disability was not an easy task. More support and courage were needed from their family, the community and government services.

Limitations, recommendations and conclusion are discussed in Chapter 4.

CHAPTER 4
LIMITATIONS, RECOMMENDATIONS AND CONCLUSIONS

4.1 INTRODUCTION

The findings of this study indicated that something needs to be done for parents who have an adolescent with intellectual disability. The family members and community members need to support those parents. Health and social services should also intervene and address these parents' challenges. These recommendations could be considered in future because children with intellectual disability are being raised to become adolescents. Interventions should start as soon as a child is diagnosed with an intellectual disability. The diagnosis could be shocking to the parents, and support systems need to be activated. Specific recommendations are discussed next.

4.2 SPECIFIC RECOMMENDATIONS TO FACILITATE MENTAL HEALTH FOR PARENTS WHO HAVE AN ADOLESCENT WITH INTELLECTUAL DISABILITY

The specific recommendations presented in Table 4.1 are based on the themes that emerged from the interviews and the researcher's field notes on parents who have an adolescent with intellectual disability.

Table 4.1: Specific recommendations to facilitate the mental health of parents who have an adolescent with intellectual disability

Themes and categories	Specific recommendations
4.2.1 Theme 1: Emotional responses experienced by parents who have an adolescent with intellectual disability	**Recommendation 1: Facilitation of the emotional health of parents who have an adolescent with intellectual disability** a) Conducting individual therapy and counselling b) Involving the parents in group therapy

Themes and categories	Specific recommendations
4.2.2 Theme 2: Experiences of support by parents who have an adolescent with intellectual disability	**Recommendation 2: Facilitation of support of parents who have an adolescent with intellectual disability** a) Facilitating family therapy and counselling b) Providing community awareness c) Providing parent support groups
4.2.3 Theme 3: Caring challenges experienced by parents who have an adolescent with intellectual disability	**Recommendation 3: Facilitation of reduction of the burden of caring for an adolescent with intellectual disability** a) Providing physical resources like wheelchairs, transportation and care centres b) Involve the parents in skills training programmes c) Guide the parents on budgeting
4.2.4 Theme 4: Positive coping mechanisms experienced by parents who have an adolescent with intellectual disability	**Recommendation 4: Facilitating the development of coping strategies** a) Conduct family counselling b) Allocation of resources

4.2.1 Recommendation 1: Facilitation of the emotional health of parents who have an adolescent with intellectual disability

As the parents experienced emotional responses, their emotional health needed to be restored. Difficulties and frustration were compounded by parents' lack of knowledge of adolescent care (Capri, 2016:22). Parents' emotional health can be restored through psychotherapy, including conducting individual therapy, offering counselling, and involving the parents in group therapy.

4.2.1.1 Conducting individual therapy and counselling

Individual therapy and counselling might help the parents to express their feelings and deal with the challenges of having an adolescent with intellectual disability with the guidance of psychiatric nurses. Parents usually visit their adolescents at the hospital and sometimes take them home for visits. Psychiatric nurses from health institutions could arrange an appointment to conduct the therapy. Psychiatric nurses could also do home visits to assess the home situation and how the parents are handling the situation of having an adolescent with intellectual disability. Some situations could be prevented through assessment and intervention.

It is the psychiatric nurses' duty to educate parents who have an adolescent with intellectual disability and empower them, especially those whose adolescents are admitted in that institution. It is difficult for parents to deal with situations they do not know about, such as intellectual disability. Parents may not know how to handle the different behaviours of their adolescents. This education should start immediately after the psychiatric nurses identified that the child has intellectual disability, to prepare the parents. Parents need to know what to expect as the child grows to an adolescent. What creates stress for the parents in having an adolescent with intellectual disability is not knowing what intellectual disability is or how to care for them. Capri (2016:92) suggests that regular training and support should be offered to parents in order to increase their understanding of intellectual disability and enhance their caring ability. Psychiatric nurses are the main source of training and support. Psychotherapists have also been shown to produce moderate improvement in parental stress (Capri, 2016:92).

4.2.1.2 Involving the parents in group therapy

Group therapy could empower those parents who have an adolescent with intellectual disability, by parents sharing experiences and how they deal with their challenges. Psychiatric nurses could assist the parents to organise themselves and meet to share their experiences. This could help them to come up with strategies to handle their situations. Orenstein (2014:5) says that group therapy provides support. He continues

that hearing from others with similar issues helps a parent to see they are not alone in their challenges (Orenstein, 2014:5)

4.2.2 Recommendation 2: Facilitation of support of parents who have an adolescent with intellectual disability

Due to the stress that parents who have an adolescent with intellectual disability experience, adequate support is required to overcome the challenges their adolescents' disability pose to them. Recent research into parents who have an adolescent with intellectual disability found that there is great need in Limpopo, one of the poorest provinces in South Africa, yet there are limited resources to support parents (Capri, 2016:91). The psychiatric nurses might facilitate support for the parents who have an adolescent with intellectual disability through family therapy and counselling, and community awareness.

4.2.2.1 Facilitating family therapy and counselling

It seemed family therapy and counselling were needed for the families of parents who have an adolescent with intellectual disability. Family members seemed to have negative attitudes toward intellectual disability due to their lack of knowledge of what intellectual disability was, and how to deal with the parents of adolescents with intellectual disability. Ackerman (2017:2) is of the view that family therapy can be used to help a family through a difficult period, a major transition, mental or behavioural health problems.

4.2.2.2 Providing community awareness

Parents want the same things for their adolescents with intellectual disability as other parents who have children without intellectual disability. Parents want to be included and supported by their communities. The community as a whole needs to be aware of mental health conditions like intellectual disability. In some communities, an adolescent with a disability is seen as a punishment to the parent. If the community could have the necessary knowledge about intellectual disability, they will provide support. The parents might then experience that they are part of the community. Even

the parents' health can improve. Through awareness, the private sector might understand the needs of parents of an adolescent with intellectual disability, and consider them when there are vacancies.

Mbwilo, et al. (2010:10) state that caring for an adolescent with intellectual disability requires many resources which cannot be provided by service facilities alone. They continue to say volunteers are required to safeguard parents who have an adolescent with intellectual disability from entering into difficulties. This can be achieved when the community knows what it means to have an adolescent with intellectual disability, and what intellectual disability means. The health sectors, together with other stakeholders, locally, nationally as well as internationally, should establish ways to keep those populations safe from the difficulties they are currently experiencing (Mbwilo, et al. 2010:10). They also state that there is a need to educate the public on intellectual disability, which may reduce the stigma and discrimination among people in the community.

4.2.1.3 Providing parent support groups

Advanced psychiatric nurses should establish support groups for parents of an adolescent with intellectual disability. These groups would empower and encourage the parents to continue in their caring duties knowing they are not the only parent with an adolescent with intellectual disability. Support groups form a community of families who truly understand and support one another (Zupanick, 2018:2).

4.2.3 Recommendation 3: Facilitation of reduction of the burden of caring for an adolescent with intellectual disability

The burden of caring for an adolescent with intellectual disability might be reduced by providing resources, involving the parents in skills training programmes, and advising the parents on budgeting.

4.2.3.1 Providing physical resources like wheelchairs, transportation and care centres

Government has to consider those parents who have an adolescent with intellectual disability, to maintain their state of health so that they can continue with care, as it is a life-long process. Parents explained that they had to carry their adolescent from one place to another, in their arms or on their back, due to a lack of physical resources like wheelchairs. The UNICEF indicated that, depending on the type and severity of the intellectual disability, an adolescent might need assistive devices like wheelchairs in order to function in various aspects of life (UNICEF, 2013:5).

Transport also seemed to be a challenge. Some parents explained that they had to save some money in order to hire transport when they have to take the adolescent home for a leave of absence because it was difficult to use public transport due to their disability, as some adolescents were bedridden, and others were wheelchair-bound. The government should allocate a special transport system at psychiatric institutions, especially where adolescents with intellectual disability are admitted. It can be expensive for the government, but something needs to be done. Some parents do not take their adolescents home for a leave of absence due to the transport challenges. The UNICEF states that the environment of adolescents with disability, like public transport, can be built in a way that facilitates access (UNICEF, 2013:22).

Due to a lack of accessible care centres, the government can encourage parents to stay with their adolescents who are manageable at home, and provide home-based care professionals to assist with care. There is only one care centre in Mopani district, and there is no space to transfer those who are at the psychiatric hospital to the care centre. The distance can also be a challenge for some parents as they cannot afford the transport. It means the parents will take a long time to visit their adolescents. The UNICEF states that children with disability and their families have the right to an adequate standard of living and are entitled to such subsidised or free support services like day-care centres, respite care and access to self-help groups (UNICEF, 2013:4).

The UNICEF encourages countries to support families and caregivers of children with disability through professional training and financial assistance to improve the quality of life for both parents and children (Badu, 2016:21).

4.2.3.2 Involve the parents in skills training programmes

Health and social services should assist by involving the parents in some skills training, such as business skills training. Parents could learn to be independent by starting small businesses to earn some money to assist them with their daily expenses. Taderera and Hall (2017:283) are of the view that psychiatric nurses can engage parents of adolescents with intellectual disability in a number of ways that can enhance their resource base. One such way is empowering parents to establish small enterprises that can generate an income to help them meet their adolescents' needs.

4.2.3.3 Guide the parents on budgeting

Parents may be earning at least some money, like receiving a social grant. It is a small grant but through budgeting, they will be able to survive. A person may have a lot of money, but without budgeting, it might be useless as they can spend the money unnecessarily. Advanced psychiatric nurses can refer such parents to social services to intervene, and include parents in the food parcels schemes with those considered to be the poor. Budgeting relieves stress over money because the parent will know exactly where each cent is going (Vohwinkle, 2018:3).

4.2.4 Recommendation 4: Facilitating the development of coping strategies

Coping with a child with intellectual disability can be very stressful, especially if your child has serious emotional and behavioural problems. Part of the parents' caring role is going to appointments with their child and ensuring that they follow any advice given. Some researchers highlighted that developing a routine and planning one's time can help one to balance the caring role with other aspects of one's life, such as working or parenting other children (Monash University Centre, 2017:5-6). Caring for oneself is critical. It is necessary to stay active and healthy, and take breaks to refresh oneself. People do not have to do all the work alone (Monash University Centre, 2017:5-6).

Extensive research emphasises the importance of support from family, friends, church and professionals in alleviating stress and facilitating positive coping abilities among parents of adolescents with intellectual disability (McNally & Mannan, 2013:2).

4.2.4.1 Conduct family counselling

Support from family members can help the parents to cope with their challenges. In the health institutions where adolescents are admitted, the advanced psychiatric nurses should provide counselling and therapy to assist parents in developing coping strategies. In that way, the parents' stress might be reduced. Cummings and Schaltz (2013:14) stress that families should seek mental health assistance for the sake of their family before things reach a point where they need counselling to help them deal with tragedies such as mental health problems or disability like having an adolescent with intellectual disability.

4.2.4.2 Allocation of resources

Sometimes it is difficult for parents to cope with having an adolescent with intellectual disability because there are no resources to assist them. There are no day-care centres or enough and accessible care centres. That is why adolescents with intellectual disability are admitted to a psychiatric hospital in Limpopo province. Depending on the type of impairment, an adolescent may need additional support and resources to fulfil their potential, including rehabilitation care, surgical intervention, assistive devices such as crutches or a wheelchair, or environmental modifications like accessible transport (Fact Sheet, 2013:13).

4.3 LIMITATIONS

In this study, the participants were limited in that only those who have an adolescent between the age of 15 to 17 years were interviewed. This was done to focus on a specific group of parents. Parents who have an adolescent with intellectual disability of other age groups' experiences of caring for their adolescents should also be heard. Only the parents of adolescents who were admitted in the psychiatric ward were involved. The researcher would have required additional time to involve those parents

whose adolescents were not admitted, as the researcher had to identify them within the community. All the participants were female because the male parents were not available as most had rejected the adolescent and their mothers. Their view was thus not included in this study.

4.4 GENERAL RECOMMENDATIONS FOR THE STUDY

After discussing the research findings, the researcher had the following general recommendations for psychiatric nursing practice, psychiatric nursing education and psychiatric nursing research.

4.4.1 Recommendation for psychiatric nursing practice

It is rare for psychiatric professionals to do home visits for parents of an adolescent with intellectual disability. Some parents indicated that they are very pleased to have been visited by the researcher because since their adolescents were admitted at the institution, no one from the institution had visited them to hear how they feel. The institution should have a programme in place to offer necessary support to those parents, as they have difficulties and need professional assistance.

4.4.2 Recommendation for psychiatric nursing education

Advanced psychiatric nurse educators should utilise the resources available to promote the atmosphere of training and learning for psychiatric nurses. Psychiatric nurses can be empowered through nursing education. The atmosphere might encourage psychiatric nurses to provide effective support to parents who have an adolescent with intellectual disability. Psychiatric nurses might empower the family and the community members so that they have a better understanding of intellectual disability and develop a positive attitude toward parents who have an adolescent with intellectual disability. The family and community members might also become supportive.

The nursing curriculum should focus on supporting parents who have an adolescent with intellectual disability through the establishment of therapeutic programmes and therapeutic group work.

4.4.3 Recommendation for psychiatric nursing research

Further research needs to be conducted on this topic to determine if the recommendations suggested were effective in improving the mental health of parents who have an adolescent with intellectual disability. The same topic should also be researched in different institutions to determine the experiences of parents living with an adolescent with intellectual disability.

4.5 CONCLUSION

The purpose of this study was to describe the experiences of parents who have an adolescent with intellectual disability in Giyani, and to develop recommendations to facilitate these parents' mental health. Phenomenological interviews were conducted. Data were analysed and themes were established.

Results indicated that having an adolescent with intellectual disability is challenging, particularly because the parents have to care for the adolescent alone. Through the analysis of the data, it was found that parents were stressed by the condition of their adolescent, as some were unmanageable. They also had challenges related to financial expenses. The lack of or limited support resulted in parents being exhausted, and this might contribute to their physical frailness. With support from family, the community, health and social services, parents could cope with their situation, and their burden of caring for an adolescent with intellectual disability might be reduced.

It seemed as if families, communities, health and social services were not providing the necessary support to parents who have an adolescent with intellectual disability; if they did, it was limited. This might be why parents who have an adolescent with intellectual disability had difficulties when it came to caring for these adolescents. Parents, family members, and the community need to receive health education and be empowered about intellectual disability in order to provide necessary support. By

doing this, the community might develop a positive attitude toward intellectual disability and the people affected by it.

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ANNEXURE A: RESEARCH ETHICAL COMMITTEE APPROVAL

FACULTY OF HEALTH SCIENCES

RESEARCH ETHICS COMMITTEE
NHREC Registration no: REC-241112-035

REC-01-90- 2018

15 August 2018

TO WHOM IT MAY CONCERN:

STUDENT: CHAUKE, T
STUDENT NUMBER: 200932427

TITLE OF RESEARCH PROJECT: The Experiences of Parents who have an Adolescent with Intellectual Disability in Giyani

DEPARTMENT OR PROGRAMME: NURSING

SUPERVISOR: Prof M Poggenpoel CO-SUPERVISOR: Prof CPH Myburgh

The Faculty Research Ethics Committee has scrutinised your research proposal and confirm that it complies with the approved ethical standards of the Faculty of Health Sciences, University of Johannesburg.

The REC would like to extend their best wishes to you with your postgraduate studies.

Yours sincerely

Prof C Stein
Chair : Faculty of Health Sciences REC
Tel: 011 559 6564
Email: cstein@uj.ac.za

ANNEXURE B: HIGHER DEGREE COMMITTEE APPROVAL

FACULTY OF HEALTH SCIENCES

HIGHER DEGREES COMMITTEE

HDC-01-59- 2018

15 August 2018

TO WHOM IT MAY CONCERN:

STUDENT: CHAUKE, T
STUDENT NUMBER: 200932427

TITLE OF RESEARCH PROJECT: The Experiences of Parents who have an Adolescent with Intellectual Disability in Giyani

DEPARTMENT OR PROGRAMME: NURSING

SUPERVISOR: Prof M Poggenpoel CO-SUPERVISOR: Prof CPH Myburgh

The Faculty Higher Degrees Committee has scrutinised your research proposal and concluded that it complies with the approved research standards of the Faculty of Health Sciences; University of Johannesburg.

The HDC would like to extend their best wishes to you with your postgraduate studies

Yours sincerely

Prof H Abrahamse
Acting Chair: Faculty of Health Sciences HDC
Tel: 011 559 6550
Email: habrahamse@uj.ac.za

ANNEXURE C: LIMPOPO PROVINCE ETHICAL APPROVAL

LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OF HEALTH

Enquiries: Stander SS (015 293 6650) Ref: LP_2018 10 003

Chauke T
University of Johannesburg

Greetings,

RE: The experiences of parents who have an adolescent with intellectual disability in Giyani

1. Permission to conduct the above mentioned study is hereby granted.
2. Kindly be informed that:-
   - Research must be loaded on the NHRD site (http://nhrd.hst.org.za) by the researcher.
   - Further arrangement should be made with the targeted institutions, after consultation with the District Executive Manager.
   - In the course of your study there should be no action that disrupts the services, or incur any cost on the Department.
   - After completion of the study, it is mandatory that the findings should be submitted to the Department to serve as a resource.
   - The researcher should be prepared to assist in the interpretation and implementation of the study recommendation where possible.
   - The above approval is valid for a 3 year period.
   - If the proposal has been amended, a new approval should be sought from the Department of Health.
   - Kindly note, that the Department can withdraw the approval at any time.

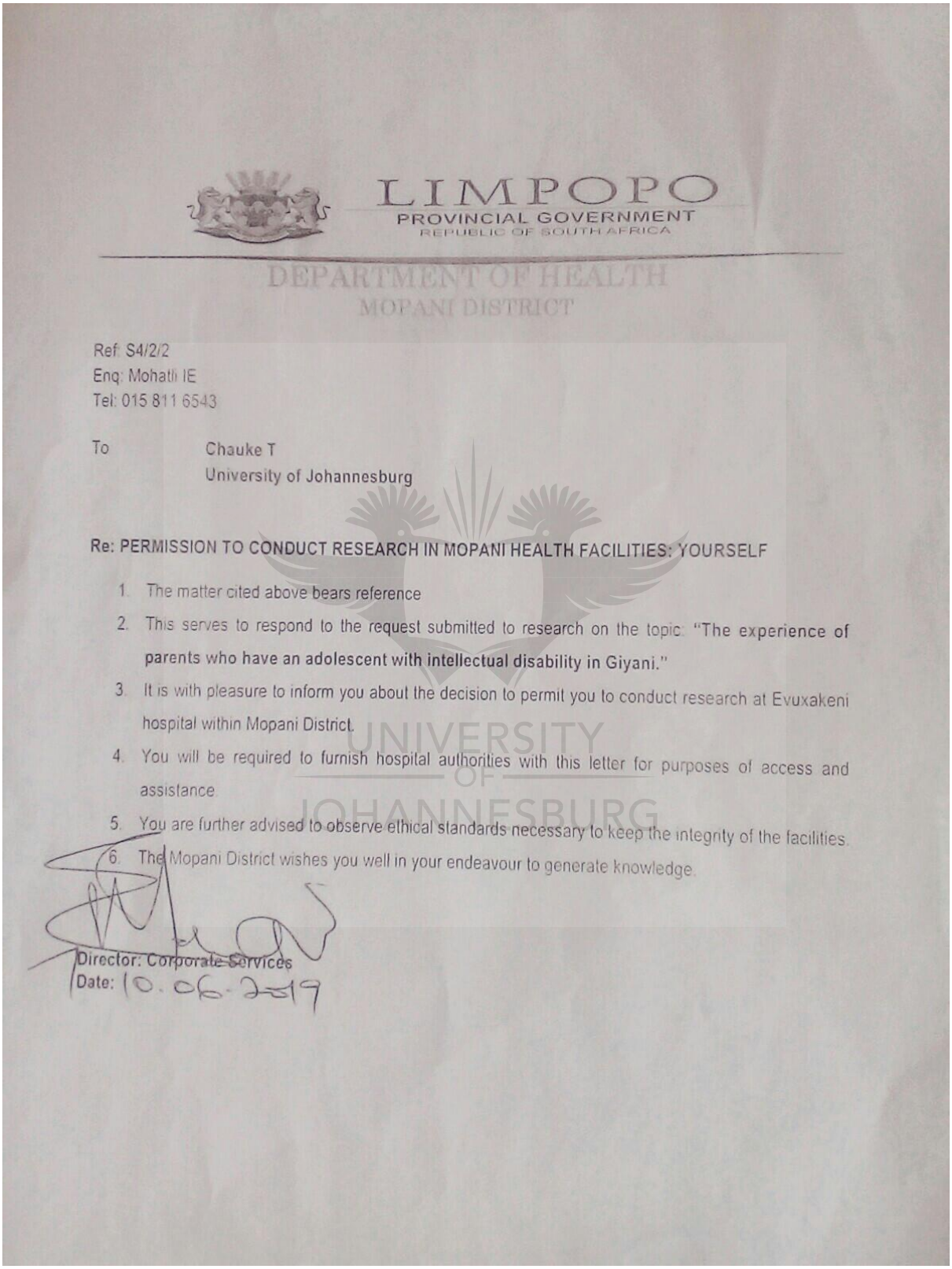
Your cooperation will be highly appreciated.

Head of Department

Date 31/10/2018

Private Bag X9302 Polokwane
Fidel Castro Ruz House, 18 College Street, Polokwane 0700. Tel: 015 293 6000/12. Fax: 015 293 6211.
Website: http/www.limpopo.gov.za

ANNEXURE D: RESEARCH APPROVALS



LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OF HEALTH
MOPANI DISTRICT

Ref: S4/2/2
Enq: Mohatli IE
Tel: 015 811 6543

To Chauke T
University of Johannesburg

Re: PERMISSION TO CONDUCT RESEARCH IN MOPANI HEALTH FACILITIES: YOURSELF

1. The matter cited above bears reference
2. This serves to respond to the request submitted to research on the topic: **"The experience of parents who have an adolescent with intellectual disability in Giyani."**
3. It is with pleasure to inform you about the decision to permit you to conduct research at Evuxakeni hospital within Mopani District.
4. You will be required to furnish hospital authorities with this letter for purposes of access and assistance.
5. You are further advised to observe ethical standards necessary to keep the integrity of the facilities.
6. The Mopani District wishes you well in your endeavour to generate knowledge.

Director: Corporate Services
Date: 10.06.2019

HOMU TRADITIONAL COUNCIL

Ref No: TA 1/1/
Enq: T/A Chabalala
Cell: 071 0488 512

DEPARTMENT OF
COOPERATIVE GOVERNANCE
HUMAN SETTLEMENTS & TRADITIONAL AFFAIRS

To whom it may Concern

This is to certify that Chauke Tsakani Mana Rudino, 7306180478087, is our resident at Homu 'B' block 14B under Induna Mavombe, Greater Giyani municipality mopani district.

The Homu Traditional Council give her a permission to interview Parents who have adolescent with intellectual disability at Homu Area, Giyani

Kindly assist

The Secretary: Hlayiso

ANNEXURE E: REQUEST TO CONDUCT RESEARCH LETTER

UNIVERSITY OF JOHANNESBURG

DEPARTMENT OF NURSING

REQUEST TO CONDUCT RESEARCH

July 2018

The Hospital Manager

Evuxakeni Hospital

Giyani

Dear Sir

I Chauke Tsakani**,** hereby **request to conduct a** research study on **"The experience of parents who have an adolescent with intellectual disability in Giyani.** In order to comply with the requirements for M.Cur in Psychiatric Nursing Science at the University of Johannesburg. This study will be done under the supervision and guidance of Professor M Poggenpoel and Professor CPH Myburgh.

I therefore request that the unit manager of the mental health ward contact parents who have an adolescent with intellectual disabilities admitted in ward 07 to invite them to participate in my research. The unit manager then can provide me with the parents' contact details, who are willing to participate, so that I can make an appointment with them to arrange for interviews.

The main purposes of this research study are:

To explore and describe the experiences of parents who have an adolescent with intellectual disability.

To formulate recommendations to facilitate parents mental health.

For these objectives to be achieved, a qualitative design study which is exploratory, and descriptive in nature will be used. The number of participants in this study is not specific but will depend on data saturation as evidenced in repeating information.

Interviews will be conducted with individual participants at their homes. The interviews will last for 40-60 minutes. The participants will be requested permission to audiotape the interview. The data will be kept under lock and key in the researcher's office. Only the researcher and supervisors will have access to the data. The data will be destroyed two years after publication of the research.

Participation is voluntary and participants may withdraw from the research if they wish to do so without any penalty. The results of the research will be made available to your institution as well as to the participants on request.

I will be delighted to answer any further questions about this research study. If you have any question regarding this study feel free to contact me at 076 247 6787.

Regards,

Tsakani Chauke, RN, B Cur (Admin et edu)

Alternatively you may contact the Chairperson of the Faculty of Health Sciences Research Ethics Committee at the University of Johannesburg who is also my supervisor:

Marie Poggenpoel, RN; PhD, fANSA

Professor; Department of Nursing

Tel: 011 559-6686

Email: mariep@uj.ac.za

You may also contact my co-supervisor:

C P H Myburgh, BSc Hons, M.Comm, D.Ed, DHE

Professor: Department of Educational Psychology

Email: chrism@uj.ac.za

UNIVERSITY OF JOHANNESBURG

DEPARTMENT OF NURSING

RESEARCH STUDY INFORMATION LETTER

July 2018

Good Day

My name is C**HAUKE TSAKANI. I WOULD LIKE TO INVITE YOU TO PARTICIPATE** in a research study on EXPERIENCES OF PARENTS WHO HAVE AN ADOLESCENT WITH INTELLECTUAL DISABILITY IN GIYANI

Before you decide on whether to participate, I would like to explain to you why the research is being done and what it will involve for you. **I will go through the information letter with you and answer any questions you have.** This should take about 10 to 20 minutes. The study is part of a research project being completed as a requirement for a Master's of Science in Psychiatric Mental Health Nursing through the University of Johannesburg.

THE PURPOSE OF THIS STUDY is to gain insight into the experiences of parents who have an adolescent with intellectual disability in Giyani and to describe recommendations that can be utilized by psychiatric nurses to facilitate the mental health of parents..

Below, I have compiled a set of questions and answers that I believe will assist you in understanding the relevant details of participation in this research study. Please read through these. If you have any further questions I will be happy to answer them for you.

DO I HAVE TO TAKE PART? No, you don't have to. It is up to you to decide to participate in the study. I will describe the study and go through this information sheet. If you agree to take part, I will then ask you to sign a consent form.

WHAT EXACTLY WILL I BE EXPECTED TO DO IF I AGREE TO? I will meet with you at the time and place that is convenient to you. I will ask you one main question namely: “What is it like for you to have a child with intellectual disabilities?” I might need to ask you follow up questions only to get clarity where there is a need to ensure that I understand exactly what you are saying.

Participant Initials:

The interview will take 40-60 minutes of your time. With your permission I will tape the interviews. These tapes will be kept under lock and key in a cupboard in my office. Only the supervisors, the researcher and the independent coder will have access to the tapes. The tapes will be destroyed two years after publication of the research.

WHAT WILL HAPPEN IF I WANT TO WITHDRAW FROM THE STUDY? If you decide to participate, you are free to withdraw your consent at any time without giving a reason and without any consequences. If you wish to withdraw your consent, you should inform me as soon as possible.

IF I CHOOSE TO PARTICIPATE, WILL THERE BE ANY EXPENSES FOR ME, OR PAYMENT DUE TO ME: You will not be paid to participate in this study and will not bear any expenses.

RISKS INVOLVED IN PARTICIPATION: No permanent risks are foreseen in this study. Some of the questions asked during the study interview might make you feel uncomfortable. Debriefing and counselling will be provided to you by the principal clinical psychologist of the hospital, Dr SS Mathebula at 015 812 1138(2030).

BENEFITS INVOLVED IN PARTICIPATION: There are no direct benefits for you to participate in this research.

WILL MY PARTICIPATION IN THIS STUDY BE KEPT CONFIDENTIAL? Yes. All data and back-ups thereof will be kept in password protected folders and/or locked away as applicable. Only I or my research supervisor will be authorised to use and/or disclose your anonymised information in connection with this research study. Any other person wishing to work with you anonymised information as part of the research process (e.g. an independent data coder) will be required to sign a confidentiality agreement before being allowed to do so.

WILL MY TAKING PART IN THIS STUDY BE ANONYMOUS? Yes. Anonymous means that your personal details will not be recorded anywhere by me. As a result, it will not be possible for me or anyone else to identify your responses once these have been submitted.

WHAT WILL HAPPEN TO THE RESULTS OF THE RESEARCH STUDY? The results will be written into a research report that will be a assessed. In some cases, results may also be published in a scientific journal. In either case, you will not be identifiable in any documents, reports or publications. You will be given access to the study results if you would like to see them, by contacting me.

WHO IS ORGANISING AND FUNDING THE STUDY? The study is being organised by me, under the guidance of my research supervisor at the Department of Nursing in the University of Johannesburg. This study has not received any funding

Participant Initials:

WHO HAS REVIEWED AND APPROVED THIS STUDY? Before this study was allowed to start, it was reviewed in order to protect your interests. This review was done first by the Department of Nursing Science, and then secondly by the Faculty of Health Sciences Research Ethics Committee at the University of Johannesburg. In both cases, the study was approved.

WHAT IF THERE IS A PROBLEM? If you have any concerns or complaints about this research study, its procedures or risks and benefits, you should ask me. You should contact me at any time if you feel you have any concerns about being a part of this study. My contact details are:

Chauke Tsakane

015 812 1138

Chauketsakani675@gmail.com

You may also contact my research supervisor:

Prof Marie Poggenpoel

Email: mariep@uj.ac.za

If you feel that any questions or complaints regarding your participation in this study have not been dealt with adequately, you may contact the Chairperson of the Faculty of Health Sciences Research Ethics Committee at the University of Johannesburg:

Prof. Christopher Stein

Tel: 011 559-6564

Email: cstein@uj.ac.za

FURTHER INFORMATION AND CONTACT DETAILS: Should you wish to have more specific information about this research project information, have any questions, concerns or complaints about this research study, its procedures, risks and benefits, you should communicate with me using any of the contact details given above.

Researcher:

Chauke Tsakane

<Signature>

Participant Initials:

ANNEXURE F: CONSENT FORM

DEPARTMENT OF NURSING

RESEARCH CONSENT FORM OR INTERVIEWS TO BE AUDIO-TAPED

THE EXPERIENCES OF PARENTS WHO HAVE AN ADOLESCENT WITH INTELLECTUAL DISABILITY IN GIYANI

Please initial each box below:

☐ I hereby give consent for my interview, conducted as part of the above study, to be audio-taped.

☐ I understand that my personal details and identifying data will be changed in order to protect my identity. The audio tapes used for recording my interview will be destroyed two years after publication of the research.

☐ I have read this consent form and have been given the opportunity to ask questions.

_____ _____

Name of Participant Signature of Participant Date

_____ _____ Date

Name of Researcher Signature of Researcher

UNIVERSITY OF JOHANNESBURG

DEPARTMENT OF NURSING

RESEARCH CONSENT FORM: INTERVIEW

EXPERINCES OF PARENTS WHO HAVE AN ADOLESCENT WITH INTELLECTUAL DISABILITY IN GIYANI

Please initial each box below:

☐ I confirm that I have read and understand the information letter dated July 2018 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

☐ I understand that my participation is voluntary and that I am free to withdraw from this study at any time without giving any reason and without any consequences to me.

☐ I agree to take part in the above study.

_____	_____	
Name of Participant	Signature of Participant	Date
_____	_____	
Name of Researcher	Signature of Researcher	Date

ANNEXURE G: INDEPENDENT CODER REPORT

THE EXPERIENCE OF PARENTS WHO HAVE ADOLESCENT WITH INTELLECTUAL DISABILITY

TSAKANI CHAUKE (MCUR)

FEBRUARY 2019

CODING REPORT by Dr N. Ntshingila

The researcher conducted 8 in-depth individual interviews until data saturation occurred.

The participants answered the questions: "?"

Central storyline: Parents of adolescents living with intellectual disability have negative emotional experiences. They had experiences of abundance and lack of support from people around them. They experienced caring challenges with their adolescent with intellectual disability and they had positive coping mechanisms.

THEMES	CATEGORIES	QUOTES
1. parents experiences emotional response	1.1 Fear of death, future	1.1 '' Ani switivi ku ta humelela yini hi N'wana loyi loko no fa" ***I don't know what will happen to this child when I die.*** "ku fanele ku rhanga yena a famba ni ta kota ku n'wi lahle" ***My only prayer is that she can die first so that I can bury her.*** "loko no fa ni siya Sibongile u ta sala Hlupheka" ***If it happens that I die first this child will suffer.***
	1.2 Worry	1.2 "Mhani wa yena a nga yingisi" ***The mother of child use to disrespect me*** "Nwana loyi u tswarile a ri kahle u lowa beburiwile hi mhani ntsonga wa yena" ***This child was born normal like other children, she fell from her aunty's back and became like this.*** "mhani wa yena u lovile a n'wi siyisa sweswi.

		The mother passed on leaving behind this child.
	1.3 Feeling that they are neglecting other family members.	1.3 " Nwana loyi anga koti ku endle nchumu" ***This child cannot do anything on her own.*** " Ni nge fanela ku tshama ni ri na yean kwala" ***I can't leave her only.***
	1.4 Sadness	1.4 " Ka mhani loko mi ni vona ni tetani ni twa ku vava" ***When you see me like this I'm in pain.*** "N'wana loyi u tshama a ri ku tweni ka ku vava a karhi a konya. ***This child is always in pain and groaning sounds day and night.***
2. parents experiences of support	2.1 • Lack of support	2.1 " Tata wa N'wana loyi ani nwi tivi" ***I don't know the father of this child, her mother died before telling me.*** "Loko ni ya exibedhlele ni vona munghana wa mhani wa Sibongile loyi ni ga n'wi vona ka xifaniso" ***When I visit Sibongile (Change the name*) in Hospital I saw the father of Sibongile who does not want a thing to do with her.*** " Eka ndyangu wa ka hina hi ntlhanu na un'we kambe ku hava loyi ani pfunaka" ***In my family we are six siblings, there is no one who is helping me.***

	2.2 abundance of support • Family members • Employers • Community • Government services	2.2 " Mhani lava ni tirhaka ka vona ni lo nyikiwa hi Xikwembu va ndzi pfuna hi swilo swo tala" ***My employer is a Gift from God, she is helping me with a lot of things.*** "Ndzi khensa ndzi vuyelela eka leswi mfumo na ti social workers va ni pfunisaka xi swona" ***I want to thank the government and social workers for their continued support.***
3.Parents experienced caring challenges	3.1 Physical frailty of the parent.	3.1 " Mina se ni ti kulerile a ni koti ku endle swilo swo tola" ***I'm aging there is a lot that I cannot do on own my own***. "Mina a ni kahle mara hi ku vana mina va ta dya yini, ni tirhela vona" ***I am tired from working the only problem, I don't know how I will support my kids***. "Mina a na ha swikoti ku tlakula Sibongile hikuva nenge wa mina wav ava" ***I can't even carry Sibongile due to the pain in my leg***.
	3.2 Poverty	3.2 "la kaya him pfa hi pfumala na swakudya" ***At times we don't have food her at home.*** "nhundzu hya tala leyi mi yi vonaka laha ni lo xaveriwa. " Makwerhu wa mina van a swa vona kambe a vi ni pfuni hi nchumu, hambi ku ri 12,5 kg yinene. ***In my family my siblings are rich but they are not supporting me***

		with anything, even a 12,5 kg of maize.
4. Parents experienced positive coping mechanisms	4.1Faith in God	4.1 " minkarhi yinwana ni nwi yisa ekerekeni leswaku va nwi khongelela" ***I sometimes take her to church so that pastors can pray for her.*** "Hambi kona loko a ni nga khongeli a ni nga ta pona" **You see me surviving like this because I'm a Christian.** " Muthori wa mina loko va ya exikhongeleni a va rivali ku n'wi khongelela. ***My employer also support us with prayer, whenever she go to church.***
	4.2 Positive coping through acceptance	Se sweswiwani mhe ni ve ni hlamusela niku phela vutomi byi nge yimi, hiku vatswari va lovili ni sale na vamakwernu, vutomi swiboha byi ya mahlweni. Xikulukumba iku na switsundzuka naa....ku ni na vamakwenu naa.. ***I have explained that this does not mean life has to ends here, just because our parents are no more and left me with my siblings, life has to go on.***

THE EXPERIENCE OF PARENTS WHO HAVE ADOLESCENT WITH INTELLECTUAL DISABILITY

Participant 2 (MCUR)

FEBRUARY 2019

CODING REPORT

The researcher conducted 8 in-depth individual interviews until data saturation occurred.

The participants answered the questions: "?"

THEMES	**CATEGORIES**	**QUOTES**
1. parents experiences emotional response	1.1 Fear of death, future	1.1 "Mhani wa yena ava vuye va adimitiwa eXibedhlele, kutani va lova. ***The mother was admitted in hospital where she passed on after a while.*** "Hi n'wi tsarisile ka ti sosayiti, hikuva a nga ta hanya ku ya kwini. ***This child is our beneficiary in our funeral policies since we all know that she will die at any time.*** " mhani wa yen ava biwe hi xitiroko hinkwalaho ka vuvabyi lebyi bya yena" **The mother even suffered stroke because of this child.** " N'wi hlayiseni Sbongile Xikwembu xi ta n'wi teka loko nkarhi wa yena wu fika" ***My employer encouraged me to look after Sibongile, she will die when the time come.***
	1.2 Worry	1.2 "nwana loyi u tshama a etlele anga koti ku tiendlela nchumu. ***This child can't do anything on her own.***
	1.3 Feeling that they are neglecting other family members.	*1.3 " Laha kaya u tshama na buti wa yena, loyi loko ni kala ni vuya anga tshamiki laha kaya"*

		When I go to work I leave her in the care of her uncle who don't even stay home once I come back "ni pfumela ku nga va mhaka ya swiphinqo leswi a nga hlangana na swona kwa ku hanyani" ***The uncle don't stay home once I come home, maybe is caused by problems that I have.***
	1.4 • Sadness	***1.4*** ....ku ni affecta swi ni affecti ngopfu. U fanele se i hleketa vutswatsi, i ehleketa ku fana na munhu lonkulu. Loko swin'wani swi nga fambi kahle, i tshama hansi i rila, ita byela mani. Loko swin'wani swi nga fambi kahle i tshama hansi i rila. Niku loko vanga fangi, ***It affect me too much. I have to think like a parent, to think like a bigger person. When something doesn't go well, I sit down and cry alone, who shall I tell. When something doesn't go well I sit down and cry, saying that, if my parents had not died...***
2. parents experiences of support	2.1 • Lack of support	2.1 '' Tata wa mbuyelo va kona va hanya, va tshama eXawela , vava nhlogorile a ha ri ntsongo va ku famba na n'wana wa wena wa xingono" ***The father of this child is alive now he is living in Chiawelo, he divorced the mother because she gave birth to a disabled child.*** " a nga si tshama a pfuna n'wana wa yena hi nchumu" ***The father is not even supporting his child***.

	2.2 abundance of support • Family members • Employers • Community • Government services	2.2 “ ni rhandza ku khensa ku pfuniwa mfumo, hi n’wana loyi. ***I would like to take this opportunity and thank the government for assisting with this child.*** “va n’wi tekile va nwi yisa eXibedhlele xa le vuxakani” ***The child was placed in a special hospital for disable children called Vuxakeni***.
3.**Parents experienced caring challenges**	3.1 Physical frailty of the parent.	3.1 “ Ni twa ku vava nyonga leyi I khale I vava, a ni swi koti ku famba hi mhaka yak u kula” ***I am not well is long I have being feeling a pain in my hip***.
	3.2 Poverty	3.2 ‘’ Mbuyelo o hola mudende hi wona wu n’’wi pfunaka swinene” ***The child is receiving a social grant, we use it for most of her needs.***
4. Parents experienced positive coping mechanisms	4.1Faith in God	4.1 Loko ako va mhaka ya ku loya Xikwembu xiendle ku ava kahle nkarhi wun'wani a swi tavaswi antswa. Se swi tlhe swi nyanya...ni gine...kumbe munhu loko akha a khongela swi pfa swi mbohla. Tani hi loko rito ra Xikwembu ri va ri kha ri chumayiriwa ri va ri ku pfuna nkarhi wun'wani. I gina i swi amukela i ku mara loko aswi nga humelelangi mina, aswi ta humelela mani. ***If God have made my adolescent to be normal,may be the situation would have been different. So it becomes worse because of her situation, I end up....when I pray I feel much better. As the word of God is being preached, it helps me so much I end up accepting my adolescent’s situation, saying that, if it did not happened to me, who should it happened to***

	4.2 Positive coping through acceptance	4.2Xiyimo lexi anga eka xona ni xi amukerili manjheni, axo ni hlupha ...axi ni vavela aku sunguleni. Emm, aku sunguleni a xini hlupha swinene, ni vuye ni gina ni xi amukela. Se ni xi amukerili. ***I have now accepted my adolescent's situation. It was difficult for me....it was painful in the beginning. It was very difficult in the beginning, but I finally accepted the situation.***

THE EXPERIENCE OF PARENTS WHO HAVE ADOLESCENT WITH INTELLECTUAL DISABILITY

Participant 3 (MCUR)

FEBRUARY 2019

CODING REPORT
The researcher conducted 8 in-depth individual interviews until data saturation occurred.

The participants answered the questions: "?"

THEMES	**CATEGORIES**	**QUOTES**
1. parents experiences emotional response	1.1 Fear of death, future	1.1 "Munhu loyi u nyikiwini, marha leaswaku a ta nyika mina a hi swona" **The child was a gift to my own child, now it looks like is my problem for ever.**
	1.2 Worry	1.2 '' hi mi karhi hi yin'wana ni kala ni endle onge ni hlanga nhloko hi mhaka leyi" **At one stage I felt like I'm about to be mad because of this child's condition.**
	1.3 Feeling that they are neglecting other family members.	1.3
	1.4 Sadness	1.4 Swa tika sweswiwani, aswi olovi ku vulavula ntiyiso. Ende loko mi kuma ku nkarhi wun'waku ni sele na vana, na support.....na family ya kona mi kuma ku support ya kona yile hansi ende on top.....kumbe ku ahi mhaka ya ku mhani ava lo famba va ya kun'wani, va lovili, na switiva ku papa n'wina na mhana n'wina va lovili. **This is difficult, truly it is not easy. You find that I was left with my siblings, there is no support... and the support within the family is very**

		low... it is not a matter of maybe my mother has gone somewhere, she is dead, I know that my father and my mother are dead.
2. parents experiences of support	2.1 • Lack of support from the father of the child	2.1 " ku tekiwa ni kala ni tekiwa kambe vukati bya kona a byi nga nyawuli" **I was married but there is nothing good that comes from that marriage.** " A hi tshama hi te tani, a ku nga ri na tirhisano" **There was no understanding between us, we use to differ a lot.**
	2.2 abundance of support • Family members • Employers • Community • Government services	2.2 " loko ni ku famba ni ya ku n'wana ku hava munhu wa ku sala na yena. **Sometimes when the child is not well I ask my neighbour to take the child to the hospital with her car.**
3.Parents experienced caring challenges	3.1 Physical frailty of the parent.	3.1 '' loko a ri mina ni hava matimba va ni tlakurisa va n'wi veka mubendweni. **I don't have enough energy to carry this child alone, I always need assistance to put her into bed.**
	3.2 Poverty	3.2 '' Laha mutini lowu ku hava a ku ri hava na yindlu yinene" **There was no house in this family.**
4. Parents experienced positive coping mechanisms	4.1Faith in God	4.1 So a...no ti byela ku, **God is in control**, hi leswi ni nga dyondzisiwa swona mina. Hiku na loko ni kha ni kula ni yingisela ku...loko ni twa ku vava....se a swi...aswi ni oloveli. Kahle-kahle mhi ni ri xiyimo lexiya, no hetelela niku ni

		yo pfuniwa hi Xikwembu ke, ku za ni fika la ni nga la. ***So I tell myself that God is in control. That is what I was taught, that when I feel hurt, I tell myself that God is in control. So it not easy for me. Surely I end in those situation, I end up telling myself that it is God who helped me up to this far***
	4.2 Acceptance	4.2 ani nyumi ku famba na yena. Futhi ni ngezi ni mi hembela. Na suka na yena kwala Giyani kwala niya na yena Bush, mhi ani na problem, ene hi famba hi public transport. Hiku mina ani ni swi amukerili ku nina makwenu wa disable, ene sweswi hi mhi mhana yena. ***I am not ashame to walk with her. I will not lie about that. I can travel with her from here to Bush using public transport. I have accepted that I have a sibling with intellectual disability and now I'm her mother.***

ANNEXURE H: TRANSCRIPTION OF EXEMPT FROM AN INTERVIEW

Participant 4	**Interviews: Experiences of parents who have an adolescent with intellectual disability**	**Themes**
Interviewer	Ni kombela mi ni hlamusela ku swi njhani ku va na n'wana la nga tsoniwa emiehleketweni, mi hlamusela hinwaswo, hi la mi nga ta kota hi kona	
Participant	Se la no tirha, ni tirha ka makwenu wa mina, n'wana mhani ntsongo wa mina, ee. I n'wana wa vumbirhi Patricia kuna buti wa yena, ivi kuta yena. Ni tshame nkarhi wo leha na yena vhele. Swi kha swi tika kwale ku tekiweni ma swivona. Ni kha ni kaya-kaya na yena. Ni hamba ni famba ni koropa na yena. Sweswo taniya. *It was difficult in my marriage, you know. I used to go around and get peace jobs. I used to go with her and do my peace jobs with her, it was just like that.* Ee, ene ku sukela ahari ntsanana, angari kahle. Loko a tshamili ami ta kuma ongete o kokiwa hi xin'wani aku ga hi xikosi, ma swivona, sweswo taniya. Mara miehleketo yo nta famba ni i....ni ya lomu swibedlele ni n'wi yisa aninga ri na yona hiku ani ani hlupheka ma swivona. Mara nuna ari kona, ari joni anga posi. Loko a fanele	**Poverty because she has no proper job**

	avuya yiva nyimpi hiku mhi ni bebule....ni famba hiku mhi nina n'wana wa xigono. Em, sweswo taniya. Se aku famba hiku una n'wana wa wa xigono, uta kuma van'wani va ta ku teka. *But that mind of...of taking my child to the hospital was not there because I was focusing on my poverty you know, I had my husband, he was in Jo'burg and not maintaining his family. He hate to come back home because I gave birth to the child with disability...he said I must leave his house because I have a chlid with disability, just like that. So he said I must go with my child, I will get somebody who will marry me.* Niku yii! Nita kuma van'wani va ta ni teka loko wena n'wini wa yena u n'wi nyenya, lava ni nga ta va kuma hi vo va ngata n'u lavaki. Ee, se hambi swiri tano ni tshama, ni kha ni famba ni tirha, ni tirhela vanhu. Ku humelela Diza ari karhi a endla switina, ni n'wi bebula hi famba ni tirha ni kha ni xava swakudya, va kha va dya ma swivona, ni ti hlayisela vana lavaya. Ee, se swi fika la van'wani va ni tsundzuxaka, akahari na Mrs Mapimele lava ava tirha a Letaba. Hi ko ni nga vutisa vaku ku n'wi tisi. Ni ye niya lava Letaba mina ni nga ku tivi. Ni famba....ni khandziya bazi ni famba ni lava a Letaba. Loko ni fika a Letaba va fike va n'wi languta-languta va n'wi cheka, va n'wi cheka kwalaya, ivi swi fika lava ni	**Poverty as the partcipant stated so.** **Rejection by the husband because of having the child with disability**

	byelaku...vange, sweswiwani a Giyani ku akiwa xibedlhele. Xibedlele lexi vari hi le Evuxakeni. Loko xita pfula ita ya kona. Ivi se va ni rhumela a Elim, eka social worker, kahari na social worker lavaya ava ku i sesi van'wani ma swivona. Ee, ivi ni ya na yena vhele ahi hlayili, va fika va n'wi tsala-tsala kwale. Va hi tsala-tsala kwalaya. Va ku va ta hi vitana loko date yi fika, loko xibedlele lexi xi pfula. Ivi hi mpela va hi vitana, ahi hlayili, hi fike hi tleletela kwale. Va pfuke va hi rwala hi movha, se va hi tisa la Vuxakeni, va hi tisa la Vuxakeni. Se ni kota ku famba ni lava ntirho, ni titirhela ma swivona. Hiku ani se aniri kaya manjheni, ni hlongoriwili. Emm, ni hlongoriwili. *So I go around looking for a job so that I can work, you see. By that time I was out of the marriage , my husband kicked me out, I was kicked out.* Ni endla sweswo hamba ni ya n'wi pfuxela vhele, ivi ni hamba niya n'wi pfuxela. Loko niri na nkarhi ni n'wi teka hi makhisimusi. Ee, se sweswiwani na nwi teka hi makhisimusi mara, heyi, se swa tika hiku se i khonyane milenge, anga ha swikoti na ku famba ma swivona. Ene loko niri na yena heyi, swa tika, swa tika swinene. *Yes, now I use to take her home during Christmas holidays but hey, it is difficult to take care of her as her legs are bent she cannot walk, you see. And when*	

	I'm with her, hey it is difficult, much difficult. No swi amukela hiku ani i n'wana wa mina, ma swivona (emotional) Ee, xikwembu xi ni nyikili ene ni nge n'wi cukumeti. Hambi sweswi anga kwalaya ani n'wi, cukumetangi hiku ani i n'wana wa mina. Ee, emm, swi ndlisa sweswo. Se i khale ni kha ni tirha kwala vhele. Ene ku sukela 2012 niri kwala. Ni vuye niti...swimalani sweswi ni swi kimaku kwalomu makhixini ni timakela xithumhani xa mina, ni tshama na vana va mina, <u>mara ni vuye ni kuma un'wani nwana, i kona a kaya. Loko ari kona akaya ate taniya ni twa ku vava, hiku na yena ahi loyi anganene, hiku xikolo i tshikili, u famba a n'wa mabyalwa, sweswo taniya. I n'hwanyani. Se loko ni tshamili ni na ku twa ku vava ku kulu. Loko niri na problem ya la nga hala, na la nga kahle hala kaya na yena ani nyika problem ma swi vona</u>. *But I had another child, she is at home. When she is at home like that, I feel pain because she is troublesome, she dropout from school, go around and drink beer, just like that. So when I think about all this, I feel more painful. When I have problem with this child, the other one at home give me problems too, you see.* Emm, unwa byalwa, ute ve ni endliseni computer, mali ya leyi ani kha ni koropa	**Rejected by her husband** **Caring challenges**

	kwala ni yi niya n'wi endlisa lahaya ka Shoprite ka Avuxeni. A dyondza 9 months hambi i 8 months ki. Ni kha ni hakela. Ixi kumili xitifikheti iyo tshama. Xa yena iku pfuka aya byaleni. Se hixi...sweswi loko ni n'wi tekile niya na yena kaya no famba ani anga swikoti. Se milenge ya yena yi khanyanili na mavoko lawa ama ha endli ku e, ya khanyanili. I..loko ni n'wi tekili kwalaya hi khisimusi ni n'wi komberili ku avhaka kaya, vo ni nyika i, i, i, maleri ya masiku ya lawa anga ta tshama wona, ni tlhe ni n'wi vuyisa. Ene loko ari kaya anga pfumeli , anga pfumeli, a rila, anga pfumeli, ee, anga pfumeli loko ari kaya. Loko i fanele u n'wi vekela pampers wo lwa anga pfumeli. I...anga pfumeli nchumu, no dodombana na yena. Leswi se mhi ni nga khegula se ni tivabyelaku na mina hi...ehe, ani switivi. Loko niku na vabya no pfa niti ni titwela sululwani, ahi mbilu, i mbilu, i mbilu. *When she is at home she is imposible, she is impossible, she cries, she is imposible, yes, she is impossible when she is at home. When you change her napkin you have to struggle, she refuses, she ...she is difficult altogether, I have to struggle with her. As now I'm becoming old and sick....yes, I don't know. When I say I'm sick, I mean sometimes I feel dizzy, is not this because of my painful heart, it is, it is.*	**Distressed – her child which is at home add to the stress that she already have beacuse of her behaviour**

	Loko nita sungula ku tirha ari Vuxakeni, ari Vuxakeni. Ene loko ari le Vuxakeni akuna un'wani an'wi pfuxelaku handle ka mina, lero loko no kubudu ni lova, angahari na n'winyi, a kungaha vi na loyi anga ta n'wi pfuxela. *And when she is in the Hospital, there is no other one who visits her except me, meaning that if I die, she will have no one, there will be no one to visit and look after her.* N'wana lonkulu u kona, ni n'wi endlise swa vusekhurithi, wa kha wa famba a koropa-koropa mara ani anga tshami na mina. Ulo na kuma nsati, ivi vo huma xitandi vani siya maswivona, ule xitandini xa yena. Wa kha wa koropa-koropa, sweswi i koropa a...hala madombija ka Usave, i sekhurithi. Mara ani no vula ku i tikoropela swa yena na vana va yena. Ku hava loyi ani nyikaku sapota, loko mi twa niku i...loko ni tshamili ni twa ku vava. Ene loko ni heta nkarhi ni nga yangi Avuxakeni, ni twa ku vava hiku se swindla ingaku nilo n'wi cukumeta ma swivona. Ee, ku hava lava ni sapotaku. Papa wa yena va hanya, mara marito ya lawaya va nga ma vulavula.... *There is no one who is giving me support, when you heard me say that....when I think about all this I feel that pain. And when I take longer to visit my child, I feel as if I have abandoned her you see. Yes there is no one who is giving*	**Caring challenges** **Physical frailness**

	me support, her father is alive, but those words that her father told me... Na vona va be hi xitiroko, va leka wheelchair sweswi. Hiku va vuye va teka un'wani wa hala Babangu, va lavela hi maxaka ya vona. Vale ka wheel chair. Vana hinkwavo na loyi u kulukumba wo sungula, na yena ava zangi va pfuka va n'wi sapotili, ava n'wi endleli nchumu kumbe ku n'wi xavela xiburukwani. Ami twi ni ngo ano hlupheka na kwale vukatini. Iri vukarini u famba u kha u tirha. Loyi anga na ntirho, ata ata vitana wena, swindli onge iyo tiya ngopfu, kuriku i vusiwana. Avari munhu wo titsamela joni na vale joni. I...anga zangi no va kurisa vana lava, ni kha ni endlisa sweswi ni nga ku swi endleni. Swikoropani swo titirhela kwala makhixini. Ha, anga zangi, futhi ava zangi. Na sweswi ava ha tirha a joni, vange se huma penceni vaya va ta ba hi xitiroko. <u>Akuri hava na siku na rin'we leri ava ya Avuxakeni va ya pfuxela n'wana luya. Ava ta a Benstolo na nsati wa vona, va ta ku holeni va xava swakudya, va tlhe va tlhela. Mara luya, ava se tshama na siku na rin'we. Mpfuka ni n'wi yisa Avuxakeni ava n'wi tivi, ava se tshama va ya nwi pfuxela. Em, ava se tshama vaya nwi pfuxela. Se hexi!</u> *There was no single day where her father visited her in the hospital to see her. He use to go to that side with his new wife to get his pay and*	**Lack of family support** **Worried that no one who will visit and care for her adolescent when she is no more** **Lack of family support** **Lack of support** **Worried that her husband has never supported her or care for the adolescent**

	buy food, then go back home. But he never went to see her child even a single day. Since I took her to the hospital, he does not know her, he never visited her. Yes, he never visited her.	
Interviewer	Se ku na minkarhi leyi mi pfaku mi ya kaya?	
Participant	Loko va ofa na mina na famba hi Wavuntlhanu hi Muvhulu ni vuya. Ami ni twi ni...ani ku nita suka niya niya n'wi vona, hiku hi Wavuntlhanu loko ni suka la nita vhe ni hunda niya le akerekeni aMoriya. Ani fanele niye hi Mugivela, anilo karhala. Hiku anii loko nitirha la , hi twelufu ni rhelela niya kunwana laya ni ya khoma peace job. Mirhi ani na wona wa karhala.	
Interviewer	Ni twe miku loko mi ri kaya na yena swa tika, mi nga ni hlamusela hiku tika ka swona.	
Participant	Loko niri kaya ni hava na wa ku ni pfuna, ni hava, ni hava. Ene se loko ni n'wi tekili, loko niya niya n'wi tlherisa ni kuma se na mina ni nga ha koti nchumu. Ee, ku hava wo ni pfuna kaya. Ene loko u fanele u n'wi nghenisa ndzeni ka bavhu swatika, ene wa oma, ih, wa oma, ani na wo ni pfuna kaya ko va mina sweswi ni ngete tani. *When I'm at home, I have no one to help me, no one, no one at all. And when I took her home, when I took her back, I found mysef very tired. Yes, I have no*	**Lack of family support** **Carring challenges**

	one to help me. When I have to put her to bath, it is difficult , she is stiff, because there is no one to help me at home, I'm by myself as you see.	
Interviewer	Mi te se mi hambanili na nuna wa nwina , se la mi tshamaku kona sweswi ku njhani?	
Participant	Hambi no suka niya na n'wina sweswi, minga fika mi vona na matshamelo ya kona kuri hee! Heyi! Ma tika (emotional). Ni tshama ka xi three rhun'wana, axilo handzuka, a xilo hlakala na munhu xi three-rhun'wana xexo, yi pandzekili andzeni, yi pandzekerili, hiku ani endla hi switina swo hisa. Ee, se ndhawu ya kho kuna muhlwa. Ene mfumu lowu wu ni pfunili, ani hlupheka, ma ku tiva ku hlupheka, ha, wu ni pfuni ngopfu, wu ni pfunili. *And this government has helped me so much by accommodating my child in the hospital.* Wo ni pfuna akaya yena ni hava, no suka -suka suka futhi haa, ani suki niya hela. Ani o tionhela atshamisi sweswi. Ene a tshamisi sweswi. Ene loko i khi i n'wi susa wo lwa. Ee, wo lwa. Buti ni na vona mara ani se tshama ni va twa vaku niya niya pfuxela lowa mzaya na siku na rin'we. *I have no one to help me at home, I don't even go out. She messed up herself sitted like that. Sitted like that. And to clean her*	**Appreciate the government for reducing her burden by accomodating her adolescent** **Caring challenges** **Social isolation as she stated that when she is at home with her**

	up you have to fight. Yes, you struggle. I have the brother but I never heard her saying he is going to visit his cousin, not even a single day. Swi ncincini, ukha u hoxeteriwa hi marito yo karhi layo vava, maku famba una n'wana wa xigono. Mara va vule leswiwani, ivi yaloyi va nga laveli hi maxaka ya vona, loyi ninge vana yena sweswi, ilo na fika a tshama kwalanu muntini, ivi na yena o bebula xigono, ih, ivi na yena a bebula xigono, yena ilo dlaya, ari nkulukumba, ari mfana yena ari tani. Se ani mina ni nge dlayi, ni nike hi Xikwembu, ani switivi ku loko Xikwembu xi ni nikise leswiya xi hlekete yini. No fanela ni swi amukela iswa mina. Leswinene aswi fanele swiya ka mani, leswo biha swiya ka mani, emm. *So I will never kill my child, it is a gift from God, I don't know His intentions of giving me this child. I have to accept it, it is mine. Who should get the good things , and who should get the bad ones.* Na mina kwala muntini wolowu ni nge ni ti akerile ximuntana, se akuna munhu, nilo siya n'wana yaloyi ninge unwa byalwa. Na yena vhele angari wa vona, nilo na vona sweswo taniya, wa ringetela swilo, kasi evo, na swona swa fana, swivula ku swile makatleni. Ih! Loko swilu u swi vona ku swile makatleni ani wo vhe i, i vhe u swi	**adolescent, she don't go out.** **Lack of family support** **Positive coping through faith**

	tshika. Ee, i hanya bya wena. Kulo sala yena na munti ari kwale. Se ani probleme ya kona i byalwa, ibyalwa. Yena i nkulukumba n'wana wo taniya, no koropa ata va a kha atikoropela. No va na ha n'wi xavela yini na sweswi. Ma swivona ku tinyikunyana ta kona teti ni nga nikiwa tona, na tona ti sukele kwale, emm. Aku naku mbilu ya wena yita rhulela ka loyi, swa fana. Yaluya Xikwembu xinga ni ...sweswiya kumbe hi yhe ata ni hlayisa. (Emotional). Ni taku yini, nita ku yini. Loko mini twa niku ee, hiku na mina na tivabyela, ani loko swiri ka wena i fanele i twa ku vava, na mirhi wu tlhe wu vava, hiku ani swivava ambilwini. I pfa i byela Xikwembu xa wena uku aredzi we Xikwembu, hi wena u swi tivaku. *There is nowhere to lean on , it is all the same.That one whom God has...may be she would have be the one who will look after me if she wasn't like that. What will I do, what will I do. When I tell you that I'm sick, is just that when you have too much problems, you will have to feel that pain in your body. So my body is usually painful. When all is in you, you will feel the pain, because it is painful inside. Sometimes you tell God that God you know all this.* Ni tshama na swona swite tani swiyimu sweswi. Hiku loko hi wavuntlhanu no ga, niku na ofa niya akaya wo wavuntlhanu walowo, ita ya abyaleni wavuntlhanu	

	walowo, ita vuya na vusiku hi ma 2,3. Migivela wolowo swiva sweswo maswi vona. Ku loko i tlele lawani, sweswi na mina phela ni pfa ni....kumbe hito ti probleme, ani switivi, ni pfa ni...kuri na tikrempe tin'wani leti pfaka ti ni khoma milenge leyi ni nga swikoti no famba, ni kha ni swi vonisa sweswo iri kwale kaya, ani swivuya ka wena hinkwaswo. *When I sleep, I sometimes... or it is because of problems, I don't know, I sometimes have some cramps at my legs and unable to walk, being surrounded by all this situations, it all come back to me.* I taku wavuntlhanu, Migivela, Sonto ari kona, ange tshami aku mhani va vuyili evo, ehe. Ha swatikoo, ko va ku swona swi tele, swa tika.	**Distressed** **Physical frailness** **Positive coping through faith** **Caring challenges due to physical frailness**

ANNEXURE I: LANGUAGE EDITING CERTIFICATE

Between the lines editing

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(BA HONS)

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20 September 2019

To whom it may concern:

I hereby confirm that I have edited the dissertation entitled: "THE EXPERIENCES OF PARENTS LIVING WITH CHILDREN WITH INTELLECTUAL DISABILITIES IN GIYANI". Any amendments introduced by the author hereafter are not covered by this confirmation. The author ultimately decided whether to accept or decline any recommendations made by the editor, and it remains the author's responsibility at all times to confirm the accuracy and originality of the completed work.

Leatitia Romero

(Electronically sent – no signature)

Affiliations

PEG: Professional Editors Group (ROM001)
EASA: English Academy of South Africa
SATI: South African Translators' Institute (1003002)
SfEP: Society for Editors and Proofreaders (15687)
REASA: Research Ethics Committee Association of Southern Africa (104)